

Running head: CHALLENGES OF OVC FOR ART ADHERENCE

**Challenges of Orphan and Vulnerable Children for Antiretroviral Treatment  
/ART/Adherence**

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**Challenges of Orphan and Vulnerable Children for Antiretroviral Treatment  
/ART/Adherence in Gulele sub city, Addis Ababa**

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**A Thesis Submitted to the School of Social Work, Addis Ababa University, in Partial  
Fulfillment of the Requirements for the Degree of Master of Social Work**

**(MSW)**

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Declaration

I, the undersigned, declare that this Master's thesis is my original work and all the sources or materials used have been duly acknowledged.

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**Thesis Approval**

This is to certify that the thesis prepared by Getenet Tadesse entitled “*challenges of orphan and vulnerable children for antiretroviral treatment /ART/adherence at Gulele sub city, in Addis Ababa*” submitted in partial fulfillment of the requirements for the Degree of Master of Arts (school of social work) complies with the regulation of the university and meets the accepted standards with respect to originality and quality.

**Signed by Examining Committee**

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*Acronyms*

AACAHB	Addis Ababa City Administration Health Bureau
AHF	AIDS Healthcare Foundation
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral therapy
BPSS	Bio-psychosocial-spiritual
EDHS	Ethiopian Demographic and Health Survey
FMOH	Federal Ministry of Health
GOE	The Government of Ethiopia
HIDO	Hiwot Integrated Development Organization
HIV	Human immune deficiency virus
HTS	HIV Testing
IAVI	International AIDS Vaccine Initiative
KII	Key informant Interview
OI	Opportunistic Infection
OVC	Orphan and Vulnerable Children
PEPFAR	President's Emergency Plan for AIDS Relief
PLWH	People live with HIV
SNNPR	Southern Nation Nationalities Peoples' Region
UNAIDS	United Nations program on HIV/AIDS
UNICEF	United Nation International Children's Emergency Fund
US PEPFAR	United States President's Emergency Plan for AIDS Relief
WCAO	Women and children Affair Office
WHO	World Health Organization

*Abstract*

*This research has conducted on the challenges of Orphan and vulnerable children to describe and explore challenges associated with ART Adherence. Many studies have been done on the HIV/AIDS and ART adherence related issues but there was little/no research done on the challenges of orphan and vulnerable children for ART Adherence. Thus, this study was conducted to describe and explore the challenges of OVCs for ART Adherence. The qualitative research design with a case study approach was employed. The study uses in-depth interview, FGD and KII as a tool for data collection. The study was conducted in Addis Ababa at Gulele sub city. The study area was selected purposively because of the high number of OVC and HIV prevalence in the area. The participants of the study were children from both sexes and different background to get a variety of views about the issue. The data had collected through both a primary and secondary sources. The general findings of this study are; OVCs on ART did not only challenging due to the loss of their parents but also they have multi-faceted ART drug associated challenges. Among them, the issue of disclosure, stigma and discrimination, opportunistic infection, and the need of affiliation groups were some of the challenges of OVCs for ART adherence. To maintain the data quality and to assure the trustworthiness, the data's obtained from different sources were triangulated. Furthermore, data's was analyzed thematically including the direct quota as necessary. Besides, the researcher has implication from social work education, practice, and research and policy point of view.*

*Key words: issue of disclosure, love and affection, proper care and support & coping strategy*

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## Chapter One

### Introduction

This study described and explains the challenges of orphan and vulnerable children for ART Adherence. The study was conducted in a developing country, Ethiopia, in its capital city, Addis Ababa, in Gulele Sub-city with selected woredas. The main aim of this study is to describe and explain the challenges of orphan and vulnerable children for ART adherence through qualitative research method. Besides, it explains the needs of OVC living with HIV/ AIDS, and to forward possible suggestions the OVCs and their care givers to improve ART adherence.

The definition of an orphan in relation to HIV/AIDS varies from country to country, with the age of children up to 15 or up to 18 years; and parental loss, mother, father, or both parents (Nthenya & Mutuku, 2018a). A vulnerable child is a child who is less than 18 years of age and whose survival, care, protection or development might have been jeopardized due to a particular condition, and who is found in a situation that precludes the fulfillment of his or her rights. It includes children who have been orphaned by AIDS and/ or affected by the HIV and AIDS pandemic, children living with sick parents, children living in highly affected communities and children living without adult care are also categorized under vulnerable children (Gudina, Nega, & Tariku, 2014). In the Ethiopian context, OVC is defined as: a child who is less than 18 years old and who has lost one or both parents, regardless of the cause of the loss. A vulnerable child is a child who is less than 18 years of age and whose survival, care, protection or development might have been jeopardized due to a particular condition, and who is found in a situation that precludes the fulfillment of his or her rights (Crivello & Chuta, 2012).

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Global estimates indicated that 17.8 million children have lost one or both their parents in the globe with HIV/AIDS epidemic; 85% of whom live in sub-Saharan Africa (United Nations International Children's Emergency Fund, 2013).

Orphans and vulnerable children are the main problems of developing countries, especially sub-Saharan Africa (Gudina et al., 2014). UNAIDS estimated that of the 16.6 million children (aged 0–17) who have lost one or both parents to AIDS, 14.8 million are in sub-Saharan Africa (United Nations program on HIV/AIDS, 2010).

Within Ethiopia 5.5 million children, around 6% of the total population, are categorized as orphans and vulnerable children. OVC comprise almost 12% of Ethiopia's total child population. The Ethiopian Demographic and Health Survey (EDHS) estimates that 72% of children in the country live with both parents, 14% with mothers only, 3% with fathers only and 11% live with neither of natural parents (Ethiopia Demographic and Health Survey, 2011).

As a result, orphaned and vulnerable children infected with HIV have been reported in multiple contexts to be at greater risk of delayed access to care, and mental health issues. Because, these children's experience many concurrent challenges including: psychosocial stressors, the need for HIV disclosure, poor adherence, fear of stigma and discrimination, managing ART in the context of adolescent development, and impending transition to adult HIV care (Sohn & Hazra, 2013).

With the start of national program for providing care and free highly active antiretroviral therapy (HAART) to children, there has been a significant reduction in morbidity and mortality of HIV infected children and more of them are surviving through childhood and adolescence (Alemu, Berhanu, & Emishaw, 2013). Along with the increased survival of children infected

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with HIV, the challenges of OVCs ART adherence remains a complex and a critical clinical issue in the care of HIV infected children (Alemu et al., 2013).

Therefore, describing and exploring the challenges of orphan and vulnerable children for ART adherence has really important for the service users and service providers to achieve the desired goal related with the issue.

### **1.2. Back ground of the study**

In 1981, a new transmitted human disease called, AIDS /Acquired Immune Deficiency Syndrome/ was first recognized among homosexual men in the United States. By 1983, the means of AIDS transmission, HIV (human immune deficiency virus) had been identified (United Nations program on HIV/AIDS & World Health Organization, 2003). At the mid1980's, this newly identified virus had spread largely throughout most of the world (UNAIDS & WHO, 2003).

There were approximately 39 million people died due to HIV/AIDS and 36.9 million people worldwide living with HIV/AIDS in 2017 (UNAIDS, 2018). Of these, 1.8 million were children aged less than 15 years old. An estimated 1.8 million individuals worldwide became newly infected with HIV in 2017 (UNAIDS, 2018)). Most of these children live in sub-Saharan Africa, particularly; eastern and southern Africa remains the region most affected by the HIV epidemic, accounts for 45% of the world's HIV infections and 53% of people living with HIV globally (UNAIDS, 2018).

As one of the sub-Saharan countries the case in Ethiopia is not different. The Federal Democratic Republic of Ethiopia has committed to reducing new adult HIV infections by 50%

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by 2020 and to ending AIDS as a public health threat by 2030. This is clearly reflected in the Country's Health Sector transformation plan II 2015-2020, where one of the major indicators is reduction of HIV incidence rate from 0.03 percent to 0.01 percent (Federal HIV/AIDS Prevention and Control Office, 2018).

In Ethiopia, based on the federal HAPCO report of 2018, the national prevalence rate was 0.91% with 613,825 people was estimated to live with HIV/AIDS and the prevalence rate of HIV/AIDS was range 0.11% in Somali (which is the lowest) and 4.98% in Gambela (which is the highest), followed by Addis Ababa (3.4%), Dire Dawa (2.5%), and Harari (2.4%). Of these, 109 201 people had been living with HIV /AIDS in Addis Ababa (FHAPCO, 2018).

The country has observed remarkable progress over the past two decades in reducing HIV prevalence rate from 3.3% in 2000 to 0.9 % in 2018, and AIDS-related deaths from 83,000 deaths in 2000 to 15,600 in 2018 (FHAPCO, 2018). However, the gains made were challenging to meet the three 90 goals of HIV prevention. The current HIV epidemiology of the country is heterogeneous, with significant variations in the burden of HIV across geographic areas and population groups (FHAPCO, 2018). To meet the second 90 target, getting 90% of PLHIV onto treatment, clients will start ART at the time of diagnosis, irrespective of their CD4 count status (WHO, 2016).

Free antiretroviral treatment has been provided to people living with HIV in many of the health facilities in Ethiopia since 2005 ( Abelti, 2013). The number of patients receiving ART has remarkably increased from time to time with rapid scale up of ART program throughout the country. This indicates that adherence for patients is very crucial element in the scale up and implementation of ART program in resource limited settings like Ethiopia (Abelti, 2013).

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Although ART service is given freely, adherence to antiretroviral therapy has been found as a major challenge in the treatment of HIV infected patients both in developed and developing countries (Marsicano, Lydié, & Bajos, 2013). The issue has also a great challenge for children's in many countries, especially for sub-Saharan once (Marsicano et al., 2013). As a sub-Saharan country; the case of Ethiopia needs greater concern to meet the three 90-90-90 HIV AIDs goals. Though, conducting a study in this issue and having detailed understanding for challenges of ART adherence particularly in OVCs have a paramount importance for everybody. Therefore, this study focuses on describing and exploring the challenges of orphan and vulnerable children for ART adherence.

### **1.3. Statement of the problem**

#### **1.3.1. Orphan and Vulnerable children**

Vulnerable children are those “whose safety, well-being, and development are, for various reasons, threatened” (Nthenya & Mutuku, 2018a). The types of vulnerability children are exposed to, are highly contextual and will vary between different settings (Nthenya & Mutuku, 2018a). The UNAIDS in National Plan of Action for Orphans and Vulnerable Children (NPA for OVC) studies defined orphans as children under the age of 18 years whose parent (s) have died, while vulnerable children are children with unfulfilled needs and rights (UNAIDS,2003).

Orphans have emerged as a significant international child concern illustrated by the results of a search of UNICEF's publications database covering the period 1996-2010 (Crivello & Chuta, 2012). During this period, the orphan problem remained rooted in concerns about the impacts of HIV/AIDS. The report on orphans and vulnerable children by the U.S. Government

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and partners estimated that, 163 million children (age 0–17 years) across the globe were orphans (loss of one or both parents to all causes) and that 17.5 million of these children lost one or both parents to AIDS (Marshall, Cardon, Poddar, & Fontenot, 2013).

Vulnerabilities are especially apparent in sub-Saharan Africa, which accounts for the highest HIV prevalence in the world combined with structural risk factors, including high poverty rates, low life expectancy, high infant and child mortality, and low education levels, particularly among women and girls (Marshall et al., 2013). Moreover, children under age 15 living with HIV totaled 2 million in 2007, with 1.8 million of these children residing in sub-Saharan Africa (UNAIDS, 2008).

There is no national wide comprehensive study conducted in Ethiopia recently regarding the situation of orphans and vulnerable children except baseline surveys by different non-government organizations in different parts of the country (Gudina et al., 2014). According to the information from these baseline surveys, orphans and vulnerable children are in difficult circumstances that call for the attention of all concerned bodies (Gudina et al., 2014). However, no study has been conducted yet in Addis Ababa; in Gulele sub city, regarding the situation of orphans and vulnerable children for ART adherence as far as the knowledge of the researcher's is concerned.

### **1.3.2. ART Adherence**

Adherence is defined as the extent to which a patient taking the right drug and dosage at the right time in the right way (Submitted & Fulfillment, 2006).

The potential of ART for long-term effectiveness is dependent upon the maximum and durable suppression of viral replication. A rate of adherence below 95% have been associated

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with failure to achieve complete viral suppression in PLWHA across the globe thus exposing them to high risk of treatment failure (Submitted & Fulfillment, 2006). Low levels of adherence can cause a rise in viral load and this may lead to the development of drug resistance strains of HIV (Submitted & Fulfillment, 2006).

Worldwide, regardless of the illness or treatment many people do not take their medications correctly (Bortich, 2016). A significant proportion of all hospital admissions and mortality are due to drug non-adherence. There is a possibility that defaulter rate is high among the youth and children under care of elderly (Bortich, 2016).

A study conducted by UNAIDS stated that; in eastern and southern Africa alone, 19.6 million people live with AIDS with 59% Children's on Anti-retroviral treatment which is less than Adults on Anti-retroviral treatment (66%) (UNAIDS, 2018). Another study in rural Uganda and urban Zambia have shown that; there was relatively low uptake of ART services among women, young people and married people with a high HIV prevalence (Hanvilay, Oshida, & Eyer, 2015). Lower levels of socioeconomic conditions, education, and income were factors strongly associated with reduced access to health care services (Hanvilay et al., 2015)

Similarly, in Ethiopia, the issue of HIV/AIDS is one of the key challenges for overall national development (WHO, 2004). It has led to a seven year loss in life expectancy, close to a million orphans and a loss of productivity and income at the workplace with severe effects at the household and community levels (WHO, 2004). A study conducted, by Federal Ministry of Health in 2017 estimated that, 738,976 Ethiopians are currently living with HIV and all of them require antiretroviral treatment /ART/ however only 426,000 people, which accounts (57.6%), are currently on ART (Federal Ministry of Health, 2017). Three regions alone (Oromia, Amhara

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and Addis Ababa) accounted for 70% of PLHIV in the country. Based on the study; the young age groups (15-24 years), there were 4,844 female PLHIV which was more than two times higher than males (with 2,143 PLHIV) (Assefa et al., 2017). Another similar study conducted in eastern Ethiopia, at Dire Dawa town stated that; ART adherence level was suboptimal (65%); whereas, the rest (35%) were non adherent (missed one or more dose) in the last seven days (Negasa, 2017).

Still another study stated that; the urban HIV prevalence is seven times higher than the rural HIV prevalence (FHAPCO, 2018). Based on; Gulele sub-city 2019, the six month report, there are 4902 HIV positive people on ART with in the ten health centers. Of these 3101 (63.2%) people on ART of these 2975 people are above 18 years and the rest 126 are children.

Besides the above figure; the research's had observed the challenges of OVC ART adherence during the filed practice one, in Zewudu Initiative (formerly known as Zewdu Initiative AIDS Support Association) and field practice two, in Zewuditu Memorial Hospital. In both of the filed practice the researcher observed that children on ART, especially the double orphan, have face problems of absence of care givers, stigma and discrimination, problem of basic needs, drop out from Scholl, ART interruption, and inappropriate disclosure of HIV status.

Moreover, Only a few studies have explored the psychosocial challenges of people live with HIV/AIDS and how they cope up their challenges in sub-Saharan Africa highlighting stigma and discrimination, lack of medical adherence, concerns about HIV status disclosure, poverty, poor academic performance, and psychological distress as major challenges (Mutumba & Bauermeister, 2015). Half of these studies is quantitative in nature, which limits our ability to

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have a rich description of how people live with HIV/AIDS cope with these psychosocial challenges (Mutumba & Bauermeister, 2015).

Furthermore, the different studies conducted related with OVC and HIV/AIDS were little or did not describe and explore the challenges of OVC for ART adherence. Therefore, this study focuses on to describe and explore the challenges of Orphan and vulnerable children for ART adherence.

### **1.4. Major Objective of the study**

The main objective of the study was to describe and explore challenges of OVC for ART adherence and their coping strategies.

#### **1.4.1. Specific Objective of the study**

1. To identify challenges of Orphan and vulnerable children for ART adherence.
2. To describe the needs of OVC on ART adherence.
3. To understand the coping strategies of OVC on ART.

### **1.5. Research Question**

1. What challenges the OVC's have about ART adherence?
2. What are the needs of OVC on ART adherence?
3. How the OVC on ART are using the coping strategies to their challenges?

### **1.6. Significant of the Study**

According to (Locke, Spirduso, & Silverman, 2013), the significant of the study indicates why you want to do the study and what you intend to accomplish. Thus, knowing the challenges OVCs ART adherence has much importance.

First, ART adherence is not an easy task since it is a life time treatment and it also needs care and support. Second, it is hoped that the research findings generated from this study has several contributions to both knowledge and understanding to our country Ethiopia and the world in general. Third, it has also contributed to the social workers and other professionals who have an interest to know the challenges of OVCs ART adherence at large. Fourth, it has useful in developing interventions that has taken into consideration the problems faced by people taking ART drug. Furthermore, the qualitative data's were collected has be too valuable to health planners such as Ministry of Health and HAPCO which leads to better designed, more directed, culturally sensitive, child focused and age appropriate intervention programs to deal the challenges of ART adherence for both service users and service providers.

### **1.7. Limitation of the study**

This study has three limitations. The study faces less coverage and no broader generalization can be made. The rest nine sub cities in Addis Ababa and six woreds in Gulele Sub city were not included in the study. Another limitation was unavailability of published reference materials on the area of the topic. The other limitation was lack of recorded data regarding the OVC in the study community.

## 1.8. Operational Definitions

***Anti-Retroviral Therapy:*** refers a lifelong drug that is used to treat HIV/AIDS.

***Child:*** is a human being below the age of 18 years old. For the purpose of this study a child is defined as a boy or a girl between 14 – 17 years of age, since the main targets of this research are children in this age category.

***Chronic HIV care:*** refers the HIV positive people health conditions and taking ART for a long period of time. As the FMOH defined that; “chronic HIV care denotes when acute HIV related infections persist in a patient for a long period of time and needs chronic care interventions (FMOH, 2009)”.

***Continuum of care:*** refers the provision of comprehensive care and support for HIV positive people/children and their families from initial diagnosis to ART adherence

***HIV positive clients:*** HIV positive means the presence of HIV virus in the body detected by either antibody or an antigen test. HIV positive clients are those people who were at some point exposed to HIV virus and infected by the virus (FMOH, 2010). In this study, HIV positive clients or people are those who know their HIV status and their test result is positive

***(Households /care givers/ parents):*** are person who may be a biological parent or not that provides care and support for the children.

***Linkage:*** the formal structure between sectors/ intuition’s or organizations to provide service for the service users through which the process of referral occurs.

***OVC refers:*** a child who lost one of both of his/her parents and/or children with unfulfilled need.

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***Referral:*** is the process that a client/patient moves through the system to ensure they receive the best care at the most appropriate level.

***Referral linkage:*** is dynamic process that links the individual seeking care and support with the appropriate service provider in time with lower cost and high access.

## **Chapter Two**

### **2.1. Literature Review**

This chapter presents a review of literature that deal with the challenges of OVCs ART adherence and the theoretical frameworks that guided the study. The gap in the literature prompted this research has also been presented.

### **2.2. Challenges of ART Adherence**

#### **2.2.1. Age and Gender**

The distribution of HIV infection rates by age groups and gender can indicate transmission levels in the sexually active population and thus guide prevention programs (Kloos & Mariam, 2007). Children and adolescents have become increasingly exposed to HIV in recent years. Rates are higher in young females than males, apparently due to a combination of the earlier commencement of sexual activity of females, the older age of their partners and gender-based biological factors (Kloos & Mariam, 2007). Age may also influence adherence and confidentiality related matters. When the child is too small his/her sero-status isn't allowed to tell themselves rather their caregivers consent is needed for both testing and knowing the result of the child. Adolescents (14 years and older) should know of their HIV status. They must be fully informed in order to appreciate consequences for many aspects of their health, including sexual behavior and treatment decisions. Testing and screening shall be voluntary and shall be encouraged along with counseling service (policy on HIV/AIDS of FDRE, 1998).

In Ethiopia, men were more likely than women to discontinue ART, but there was no clear explanation for this gender difference (Mekonnen, Sanders, Tibebu, & Emmart, 2010). An assessment of the uptake of ARVs in Malawi found that men are unlikely to access treatment out

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of fear of marital discord, because men testing positive are perceived to have contracted HIV because of infidelity. Given that the desire for marital harmony affects men's willingness to access testing services, many men face a barrier in obtaining and maintaining treatment (FHAPCO, 2015)

Depending on social and cultural norms related to gender, one's gender can increase personal vulnerability to HIV and influence one's ability to access information about preventive measures, care, support, and treatment. Hence, gender inequity is recognized as a major barrier to effective care, treatment, and prevention efforts (WHO, 2003 & Herstad, 2010).

### **2.2.2. Educational status**

Proper education of patients before the initiation of and during ART is important for the success of adherence. Strategies such as education should cover basic information about HIV and its manifestations, the benefits and side effects of ARV medications, how the medications should be taken and the importance of not missing any doses (Bortich, 2016). Adherence assessment should be combined with adherence counseling at each visit (Bortich, 2016).

A Lower level of general awareness, education and poorer literacy impacts negatively on some patient's ability to adhere however, a higher level of education and awareness has a positive impact for effective referral linkage and treatment. Clients' knowledge about the disease, low understanding about the importance of ART adhering to treatment schedules, forgetfulness, accepting unpleasantness of the medications, confusion on dosages, and others mostly related with low level of education. Therefore, a collaborative effort of all stakeholders about the comprehensive understanding for referral linkage to ART adherence is a needy task (DeWalque, 2006).

### 2.2.3. Stigma and Discrimination

Stigma is defined as an attitude and behavior toward a social group of a set of people based on some physical, behavioral, or social trait perceived as being different from the group norms (Jean, 2015). HIV/AIDS has created new opportunities for the manifestation of stigma and discrimination to people who are infected with and affected by epidemic (Jean, 2015). HIV related stigma refers to all unfavorable attitudes, beliefs, and policies directed toward people perceived to have HIV/AIDS as well as their loved ones, close associates, social groups, and communities. Addressing and scaling up efforts on stigma and discrimination in neighborhood, communities, and school settings; and developing guideline for disclosure of children with HIV/AIDS in Ethiopian context will increase the rate of disclosure of children's HIV positive status on highly active antiretroviral therapy (Alemu et al., 2013).

UNAIDS defined as: HIV/AIDS-related stigma is an attribute or quality which “significantly discredits” PLHIV who are on ART in the eyes of their family, community, and health care providers (UNAIDS, 2002).

The other study also explained as, denial and fear of disclosure due to stigma and discrimination against HIV/AIDS-affected people contribute to fuelling the epidemic in communities where a sense of unity and integration or connectedness is weak and HIV/AIDS are seen as a framework of transgression, stigma and punishment (UNAIDS, 2005). Stigma and discrimination have taken in Ethiopia not only at the work place, in housing, health facilities, schools, and in family and personal relationships but also in the medical services, discouraging people from being tested for HIV ( UNAIDS, 1997).

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Another study also described as, HIV related stigma significantly impacts on uptake of HIV testing, negative attitude of services providers, and adherence to HIV treatment and follow up. This reinforces the social constraints of cultural acceptance of medical initiatives (Wasti, Simkhada, Randall, & Teijlingen, 2009). Due to stigma and discrimination people are less likely to undergo HIV test and seek treatment PLWHA hide their disease due to the fear of the separation as well as stigma sculptured by the mass media (Wasti et al., 2009).

### **2.2.4. Financial concerns**

There is evidence in the pioneering studies on adherence in resource-poor settings to suggest that medication-related costs are one of the main challenges to ART adherence (Bortich, 2016). Studies revealed that patients on higher incomes have less difficulty with adherence. However; poverty is an increasing feature of the face of HIV especially in the third world where many people are living below the poverty line ( Grierson, 2000). Owing to multiple factors which are a challenge to adherence to HIV/AIDS treatment, indicated that poverty affects the adherence to care (Kheswa, 2014). Furthermore, combined stresses associated with poverty such as inadequate housing, unemployment and forced relocation tend to aggravate the health condition of people who had already started their treatment. Effects of poverty such as shelter, hunger, violence from others, and lack of social support contribute immensely to non-adherence to ARV treatment (Kheswa, 2014).

High rates of adult mortality in Ethiopia coincide with widespread poverty. Ethiopia is one of the world's poorest nations and in 2010 was ranked 157 out of 169 countries on the human development index (UNDP). Ethiopia's household income and consumption expenditure survey (2004/5) identified 38.7 per cent of the country's population as poor (Crivello & Chuta, 2012). Transportation issue, poor dietary practice, low level of technological information,

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medications and clinic visits cost may challenge the service provision and the quality of referral linkage activities carried on time. Women and children's economic dependency greatly limits their decision making power within the family, and their access to finance and other resources. Measures to be taken to reduce poverty that exists gender inequalities (Millennium Development goals, 2005).

### **2.2.5. Religion and ART Adherence**

Spirituality/religion is a complex construct that can incorporate the internal, personal, and emotional expression of the Sacred and the formal, institutional, and outward expression of the Sacred (Ayuk, Udonwa, & Gyuse, 2017). Spirituality has long been linked with health and wellbeing and may be a central issue for patients at the end of life or those dealing with a chronic illness such as HIV/AIDS (Iron son, & Kremer, 2006). Research indicates that people reflect on their spirituality after being diagnosed with HIV/ AIDS by incorporating their understanding of God and previous religious and spiritual experiences as part of their coping repertoire (Ayuk et al., 2017). Therefore, patients with HIV/AIDS use spirituality and religion as a coping strategy and to bring a sense of meaning and purpose to their lives in the face of a challenging illness(Ayuk et al., 2017). Both play crucial roles in guiding the decisions of people with HIV/AIDS about taking antiretroviral treatment (Kremer, Iron son, Schneider, & Haut zinger, 2006)

Another study also showed that there is a connection between religion and ART medication experiences. For example, Nigerian PLWHA viewed ART medication efficacy to be dependent on Allah's dispositions. Islamic perspective dictates that Allah influences the discovery, emergence, and provision of ARVs. Islamic faith also encourages PLWHA to seek treatment, since all "...servants of Allah must seek treatment for diseases" (Balogun, Amusa &

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Saheed, 2010). A similar theme emerged in the qualitative, semi-structured interviews of Malawian healthcare providers. Most providers attributed religion to their patients' non adherence because patients stopped taking their ARVs after being prayed at in church and during fasting (McKinney & Ogbochi, 2014)

### **2.2.6. Social support**

Having a partner, social or family support, peer interaction, and better physical interactions and interpersonal relationships with the communities are characteristics of adherent patients. Living alone and a lack of support have been associated with an increase in low and non-adherence (Williams & Friedland, 1997). Researchers and experts in the field have indicated that social support from family, friends, and/or healthcare professionals has been found to diminish depressive symptoms among HIV positive individuals (Jean, 2015). Conversely, individuals with less social support are less able to cope with the challenges related to HIV and experience more negative outcomes (Jean, 2015). Good social support has been influence adherence positively (Bonichon, 1957). This involves supporting the PLWHA throughout his treatment by providing motivation, routine adherence counseling, involving the PLWHA in treatment decisions, open communication, compassion and taking regimen inconveniences into account to improve adherence (Bonichon, 1957). On the other hand, living alone and a lack of support have been associated with an increase in non- adherence (Williams & Friedland, 1997).

### **2.2.7. Counseling**

Counseling provides an important opportunity to deliver how to use the ARV drug nutrition messages to HIV-positive clients immediately after testing as well as to encourage adequate nutrition practices among HIV negative clients. HCT counselors need periodic updates on nutrition issues related to HIV/AIDS (FMOH, 2006).

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All clients undergoing HIV testing should be provided with counseling in person (as individual or couple): The post-test counseling session depends on the test result; For positives, sessions will focus on meaning of HIV positive result, coping with the test result, providing information on test & start, importance of medical care and treatment, disclosure and partner testing, prevention messages, positive living & referral for care and treatment (FMOH, 2017). The relationship between the counselor and the patient is a critical component of success. Trust has to be earned through genuine and nonjudgmental interactions (WHO, 2018). More directive approaches to counseling may work better for adolescents. Counselors should be active, asking questions and suggesting topics of discussion. Skills-building activities can be included in counseling with adolescents (for example, role-playing, decisional balance activities, homework) (WHO, 2016).

### **2.2.8. The system of care and support**

In Ethiopia, HIV positive clients are usually referred to chronic care using a referral form. Currently, three referral processes are being practiced as follows (FMOH, 2017): The first one is Passive referral by which clients are sending to chronic care by themselves with the referral form. In the second, Clients referred and accompanied by counselor or provider. In the third Clients referred and escorted by adherence supporters. Adherence supporters are known HIV Sero-positive people who help the health care providers with counseling new HIV positive clients to adhere to services and drugs (FMOH, 2017).

An important role of care and support is its impact on prevention and behavioral change strategies. The literature emphasizes the integral connection between care and support and prevention strategies. In a study conducted in rural Thailand, increased contact with PLWHA over time resulted in more tolerant and receptive attitudes towards PLWHA and HIV/AIDS

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(Takai, 1998). Providing counseling support facilitated family and community acceptance of PLWHA and affected behavioral change such as increased condom use (Kaleeba, 1997). When care and support are provided in the community, awareness and acceptance of HIV/AIDS as a community problem is promoted. Further studies have shown when care and support are provided, people are more inclined to reveal their HIV status, understand the need for prevention, and are motivated to protect others as opposed to when no services are provided and they feel abandoned by the health care system (Mac Neil & Anderson, 1998).

Lack of clear instructions and direction, poor implementation, absence/poor/ feedback mechanisms, low follow system, low educational messages and others are some of the challenges of ART adherence in system of care. The WHO updated its guidelines on ART in 2015 and recommends combination of two NRTI's (Nucleoside reverse transcriptase inhibitor) and one ARV from another class as the preferred first-line therapy for treatment initiation in adults, adolescents and older children (WHO, 2015).

### **2.2.9. Side Effects and fear of medications**

Fear of adverse effects of medications can affect patient willingness to initiate or to continue treatment. HIV treatments are very complicated and often require the patient to take several medications at varied doses with restrictions on food intake and activities. Pill burden is one the major reason for medication non adherence. Research also shows that less adherence can lead to various side effects apart from the prognosis of HIV to AIDS. Adverse effects of medications can negatively affect adherence. Some persons will self-discontinue medications; some will selectively discontinue some medications and some will drop out of care. Side effects can negatively impact doctor patient relationship and suboptimal adherence is associated with

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treatment failure, emergence of drug resistance, and disease progression (www.aidsetc.org March, 2012).

### **2.2.10. Coping Strategies**

Coping strategies are defined as things people do to avoid or minimize the stress that would otherwise result from problematic conditions of life (Arts, Soc, Haruna, & Haruna, 2014). They also explained that coping involves both having resources and using various coping strategies. Coping at individual level include; one's education, income, self-esteem, sense of mastery, and psychological hardiness (Arts et al., 2014).

Antiretroviral drugs have converted the daily life of HIV infected individuals. Although HIV positive individuals are no longer confronted with a rapid and fatal prognosis, they still have to cope with living with a chronic disease (Kohli, 2016). Research suggests that coping styles greatly influence the psychological impact of HIV infection. The use of positive coping strategies has been shown to be associated with the decrease in mood disturbance, lowering distress, and slower disease progression (Kohli, 2016).

The Chinese character for crisis is a combination of two words: danger and opportunity. People who fully engage in recovery from trauma discover unexpected benefits. As they gradually heal their wounds, survivors find that they are also developing inner strength, compassion for others, increasing self-awareness, and often the most surprising a greater ability to experience joy and serenity than ever before (Reactions & Reactions, 2003).

In the study carried out by UNICEF (2010) in Zimbabwe confirmed that school performance for OVC deteriorated partly because of the need to engage in income generating activities and partly because of anxiety. Other coping strategy adopted by OVC includes using

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their scholastic materials sparingly by writing in all the lines in the book and ensuring that all pages are integral (Hlatywayo, Zimondi, & Taurai, 2015).

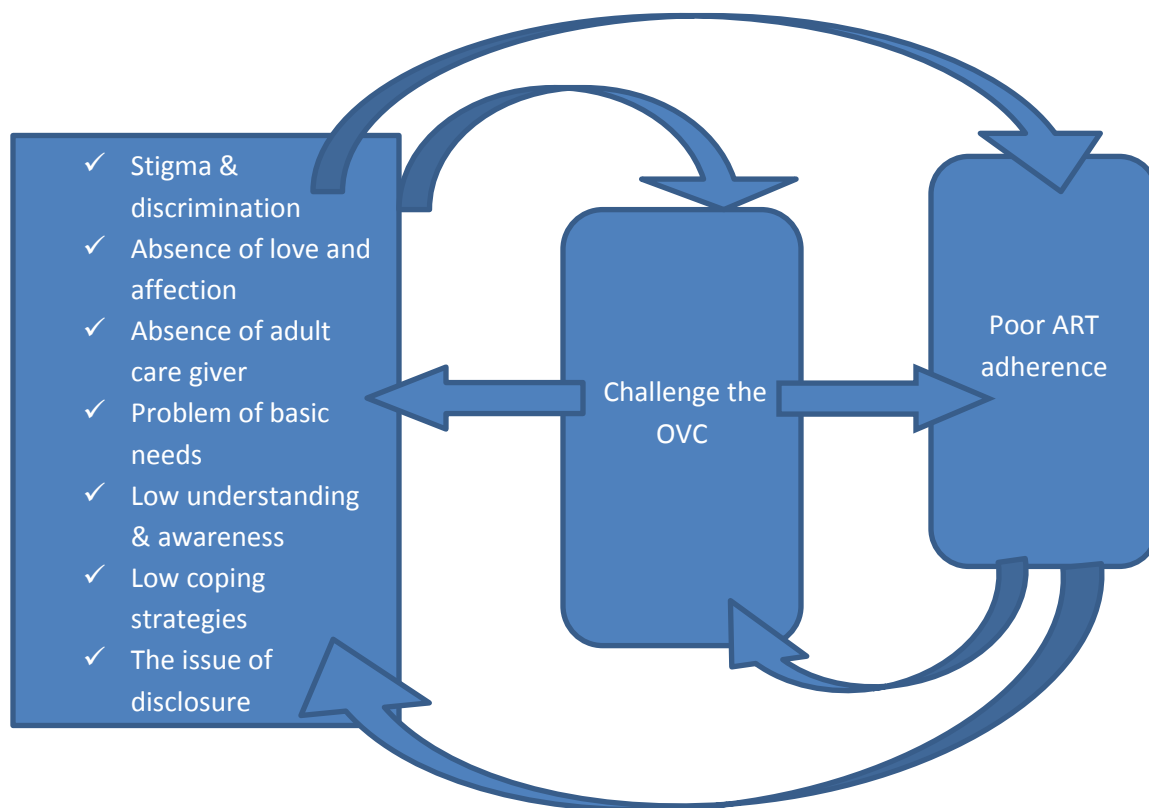
### **2.3. Conceptual Frame Work**

A conceptual framework is an interconnected set of ideas about how a particular phenomenon functions or is related to its parts. Every research activity is conceptualized and carried out with in some contextual frame work (Mugisha et al., 2009). Testing theory does not have to be the beginning point of a qualitative empirical study; instead qualitative research often explores areas that are understudied and searches for emergent theory (Creswell, 2003). A conceptual framework grounds the study in the relevant knowledge bases that lay the foundation for the importance of the problem statement and research questions. The framework serves as the basis for understanding the causal or correlational patterns of interconnections across events, ideas, observations, concepts, knowledge, interpretations and other components of experience. Theory may not be guiding the study but concepts are (Monyau et al., 2012).

The goal of a conceptual framework is to categorize and describe concepts relevant to the study and map relationships among them. A conceptual framework grounds the study in the relevant knowledge bases that lay the foundation for the importance of the problem statement and research questions. It enables the researcher came-up with a synthesis of concepts and perspectives drawn from many sources (Rocco & Plakhotnik, 2009).

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As a result this study has used the following diagram as a conceptual framework.



### 2.4. Critical issues for the literature review

In this part the researcher has tried to put the gaps observed on the previous studies about the issues being studied. Therefore, the researcher has putted the following points as a critical issue:

1. Regarding to age and gender the studies had left the OVC and/or did not due empathies at all.
2. Concerning to educational status the study did not told anything about how the prior knowledge and understanding about the issue impacts/challenges their life were not addressed.

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3. Regarding about stigma and discrimination the way how stigma and discrimination manifested /committed were not clearly explained. Besides, the study did not specifically see the issue of OVC rather it looks for all PLWHA.
4. Regarding the financial concerns the studies did not look the challenges of OVC to get a source of income and it missed the absence of primary care givers in their life. Besides the studies were conducted during the time when the ART drug not available for all freely. There for the challenges for ART adherence with cost and free from cost may really different.
5. Concerning to the social support, to maintain the OVC on ART adherence, the roles of individuals, families, communities, institutions/NGOs and the government were not clearly stated by the previous studies.
6. Regarding the side effects of the drug the challenges between the OVC and their primary caregivers'/households were not due attention.
7. Regarding coping strategies, how the OVCs and their families used to cope up their daily issues about ART adherence did not well describe.
8. Generally, the studies conducted related with ART adherence has left the OVC rather they gave due emphasis for Adults. Whereas, the few studies conducted on OVC did not focused about the ART of the children. .

## Chapter Three

### 3.1. Research Paradigm/Philosophical Stance

#### 3.1.1. The Constructivist Worldview

Constructivism or social constructivism is a perspective, and it is typically seen as an approach to qualitative research (Berger & Luekmann's 1967). Constructivism is basically a theory which is based on observation and scientific study, that people construct their own understanding and knowledge of the world, through experiencing things and reflecting on those experiences (Olusegun, 2015). In any case, we are active creators of our own knowledge. To do this, we must ask questions, explore, and assess what we know (Olusegun, 2015). Individuals' develop subjective meanings and understand their experiences towards certain objects or things. They also focus on the specific contexts in which people live and work. Researchers recognize that their own backgrounds shape their interpretation, and they position themselves in the research to acknowledge how their interpretation flows from their personal, cultural, and historical experiences. They also interpret what they find, an interpretation shaped by the researcher's own experiences and background. The goal of the research is to rely as much as possible on the participants' views of the situation being studied, (Lincoln, Lynham, & Guba, 2011) and (Martens', 2010). Thus, qualitative researchers seek to understand the context or setting of the participants through visiting this context and gathering information personally.

#### 3.1.2. Research Design

As (Burns & Grove, 2003) define a research design as: a blueprint for conducting a study with maximum control over factor that may interfere with the validity of the findings.

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A qualitative approach enables the researcher to get an in-depth understanding of the issue and allow research participants to express their views broadly. It is a more appropriate in terms of documenting rich and detailed information (Snap & Spencer, 2003). A qualitative research is the best when the issue of concern at hand needs exploration, comprehensive understanding of the context and the phenomenon (Creswell, 2007). Qualitative research is mostly associated with words, language and experiences rather than measurements, statistics and numerical figures. As a result, the study has used a qualitative research to get in-depth understanding about the challenges of OVCs for ART adherence.

### **3.1.2.1. Case Study Approach**

A case study is an appropriate study approach for that it gives a wide opportunity to explore the distinctive and multifaceted experience of the targeted population of this study. Case study methods involve systematically gathering enough information about a particular person, social setting, event, or group to permit the researcher to effectively understand how it operates or functions. It allows the investigator to retain the holistic and meaningful characteristics of contemporary phenomena and real life event desire to understand complex social phenomenon (Yin, 2003). In addition, case study can provide robust and important information about the issue by using various information sources (Padgett, 2003) Therefore, the study aimed to get detailed and appropriate information about the challenges of OVCs for ART Adherence.

The study has used a multiple case studies to investigate several related cases of a similar phenomenon and involve two or more people or groups where the group is considered a unit or case of something. Multiple cases allow for a multiplicity of voices (perspectives) to be heard and enable the researcher to subsequently draw on multiple data sources during analysis and writing (Anderson, 2016). The intrinsic case study will help to undertake when a researcher

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wants to better understand a particular case of interest because of its uniqueness or ordinariness. The researcher needs to be able to define the uniqueness of this phenomenon which distinguishes it from all others. The role of the researcher is not to understand or test abstract theory or to develop new theoretical explanations; instead, the intention is to better understand intrinsic aspects of the particular child, patient, criminal or organization (Anderson, 2016).

### **3.1.3. Study area**

In case of qualitative research, for the purpose of deep understanding of the subject matter under study or research question, it is up to the researcher to make a decision on the research participants, sites and even the material to use (Creswell, 2007). The study area of the research was in Addis Ababa. The City has 10 sub cities and 116 woreda's with diverse population. Addis Ababa city administration health bureau, which was established in 1993, is responsible for the overall health care services delivery of the city (Addis Ababa City Administration Health Bureau (AACAHB, 2015).

The study was conducted in Gulele sub city at the North part of Addis Ababa. The study area was selected purposively based on the preliminary assessment. During the preliminary assessment the researcher observed that many OVCs found in the sub city have different challenges related with ART Adherence. The other rationale for selecting this area from others was; it is one of the sub cities that have more orphan and vulnerable children (AAHAPCO, 2018). Before the onset of the data collection the area was visited and potential areas were identified. On top of that, during the preliminary assessment, the researcher observed that the sub city has relatively less industrial with high number of NGOs and local associations in the sub city. Since these NGO's and associations are working for long in HIV/AIDS related issues, the researcher understands that, it could be an asset for the success of the study.

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According to, Addis Ababa HAPCO, Index case testing, care & support plan of 2018 G.C showed the HIV testing and expected yield is as follows (AAHAPCO, 2011 E.C):

Table3.1. Index case testing, care & support plan of 2018 G.C.

<i>Sub-cities</i>	<i>Number of Woredas</i>	<i>HTS target per year</i>	<i>Yield</i>
Akaki-Kality	9	5000	225
Addis Ketema	9	5,500	248
Arada	10	5,250	236
Bole	13	5,200	234
Gulele	9	5,600	252
Kirkos	9	5,500	248
Yeka	12	5,250	236
Kolfe	12	5,500	248
Lideta	7	3,500	158
Nifas Silk lafto	10	5,420	244
Total A.A	100	51,720	2,327

Source: Addis Ababa HAPCO, Index case testing, care & support plan of 2018 G.C.

### 3.1.4. Sampling method

The target populations of the study were HIV positive OVCs who are living in Gulele sub city. The researcher has also used primary care givers/ household's/ and other key informants working related with the issues as a source. Merriam (1988), stated that, sampling in qualitative study tends to be small number of people nested in their context and studies in-depth unlike quantitative studies, which aim for large number of context of stripped cases and seek statistical significance. Purposive sampling was employed to select the research participants and in order to

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make sure that different attributes like age, sex, socio-economic status, and other factors are represented in the research. Purposive sampling is believed to be the best method to reach the neglected and/ deprived segments of the population. In addition, purposive sampling provides options when a targeted sample needs to be reached quickly to make generalizations from the results that are being studied.

Regarding the data saturation; data saturation is not about the numbers purse, but about the depth of the data. A large sample size does not guarantee one will reach data saturation, nor does a small sample size rather, it is what constitutes the sample size (Ness & Fusch, 2015).

### **3.1.5. Participants**

In this study there are 21 individuals who were participated. The researcher was used eight HIV positive OVCs as a study participant in in-depth interview from the target groups of Hiwot Integrated Development Organization/HIDO/. The study also repeated the 8 HIV positive OVCs as one FGD and 8 primary care givers/ households as the second FGD in different time. Besides the study also used five key informants (one from Gulele sub city HAPCO office, one from HIDO's referral link officer (working in Gulele sub city as ART counselor for woreda 3, 4, and 5 health centers), the other one from Gulele sub city woreda seven health center (disease prevention and control as well as HIV/AIDS focal person), and the rest two are case managers from woreda 7 and 9 health centers).

#### **3.1.5.1. Participant's selection Criteria**

The participants for the study are selected by a purposive sampling technique in order to recruit and secure adequate and reliable data. Purposive sampling technique involves the use of the researcher's knowledge of the population in terms of research goals (Gilgun, 2017).

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- The willingness of the participant's to take part in the study
- The researcher's interest to conduct a study about the issue
- The OVCs were enrolled in care for vulnerable children project, as a target group of Hiwot Integrated Development Organization/HIDO/ and had participated in life skill and financial capability training which is given for OVCs 14-17 years old.
- Moreover, the OVCs participated in the study has living more than six months in Gulele sub city and has lost at least one parent's and vulnerable.
- The OVC should be an HIV positive

### **3.1.6. Methods of Data Collection**

#### **3.1.6.1. Primary sources of data**

The primary sources of data were semi-structured interview and focus group discussion. A semi-structured interview is a method of collecting data where a flexible interview guides a single interviewer who uses active listening and probing to allow for detailed and understanding (Forrester, 2010).

The data collection of the study was conducted with a period of four weeks from March 26 /2019 until April 26/2019 and it was facilitated with the social service workers of HIDO. In general, including the time of proposal, this study has conducted from November 15/2018 until June 14/ 2019 in its date of summation.

##### **3.1.6.1.1. In-depth Interview**

In-depth interview was employed as a major tool of data collection during study. Individual in-depth interviews were conducted with HIV positive OVCs. Primary data were collected using this method from 8 OVCs, (4 HIV positive OVCs who are boys and 4 HIV

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positive OVCs who are girls). Detailed information was also obtained regarding their life situations, the ups and downs they have faced, life choices they have made and the day to day decisions they make in order to overcome the challenges and sustains in their life. The researcher has prepared an interview guide that was composed of open ended questions and had collected qualitative information using the interview guide.

Such a data collection method has many advantages. It helps to get “other kinds of information that do not easily get into the public record” (Yow, 1994). If a participant does not understand a question(s) in an interview, the researcher can fill in, and if, the researcher senses the respondent is not answering fully, he/she can probe for more complete information (Bernard, 2006). Besides, the physical presence of the researcher will help to establish the rapport needed for asking sensitive questions including personal questions about painful experiences of participants. The in-depth interview has taken an average of 50 minutes for each interviewee.

### **3.1.6.1.2. Key informant interview**

Semi-structured questions were used as a tool of data collection to describe and explore the challenges of OVCs for ART adherence and how social work intervention could be put in place to overcome those challenges. It helps to gather information's from the key informants in order to analyze the challenges of OVCs ART adherence. The study had five key informants (one from Gulele sub city HAPCO office, one from HIDO's referral link officer (working in Gulele sub city as ART counselor for woreda 3, 4, and 5 health centers), the other one, from Gulele sub city woreda7 health center (disease prevention and control as well as HIV/AIDS focal person), and the rest two are case managers from woreda 7 and 9 health center). This helped the researcher to obtain enough data about the challenges of the OVC on ART. The researcher has used an average of 40 minutes for each Key informant interview.

**3.1.6.1. 3. Focus Group Discussion /FGD/**

Focus group discussion is a qualitative data collection technique in which a selected group of people discusses a given topic or issue in-depth, facilitated by a professional, external moderator and serves to solicit participants' attitudes, perceptions, knowledge, experiences, practices, and interaction with different people (Eeuwijk & Zuzana, 2017). The objective was to give the researcher an understanding of the participants' perspective on the topic in discussion. The participants have given the same issues: to discuss each other and to observe their confidence, and to speak about their experiences in a way which may not occur in one-to-one interviews (Bernard, 2006). For FGD, it is recommended that the size of the group include between 6 and 12 participants, so that the group is small enough for all members to talk and share their thoughts in detail, and yet large enough to create a diverse group (Fusch & Ness, 2015).

In this study there were two FGDs: the One is the HIV positive OVCs and the other one is the household's FGD. Both of the FGDs have conducted in different time in the same place which is convenient to conduct the study. Focus group discussion as a data collection method were used in this particular study in order to see their confidence, their way of understanding the problem, their challenges, the way how they cope-up the problem, to find out their assets and needs, to observe their communication and cooperation with others in general.

The focus group discussion was held in HIDO's meeting hall. But, since the participants were come from different places the discussion were conducted with refreshment such as tea, coffee, milk, cookies and soft drinks. The discussion has spent an average of 45 minutes duration for each FGD.

### **3.1.6.2. Secondary source of Data**

Besides primary data, the researcher has used a variety of secondary source of data from published and unpublished materials like books, reports, leaflets, brochures, magazines and newsletters related to the study have been and other necessary materials were also collected to expand my understanding about the problem and support the first-hand information gathered in the field. Different reports from international, national and other development actors' publications that focus on OVCs ART adherence were used. Different researches, publications and articles focusing on the issues were also considered in general. Besides, different national and international policy documents, strategy papers and guidelines that have been developed in the area were used in order to see how the issues was too challenging and needs joint effort. Literatures about HIV/ AIDS in general and OVCs on ART adherence in particular, other similar case stories from other sources and other countries were also be used to feed up the research and strengthen the results. Therefore, secondary information helped the researcher to see the gap in the existing literatures on the participants, to make sure that the relevance of this study with previously conducted studies, to produce a more valuable research.

### **3.1.7. Data Analysis**

Data obtained using in-depth interview, key informant interview, focus group discussion; and document review were analyzed and interpreted thematically. The data's gained from them was also transcribed and analyzed critically. It involves classifying responses into meaningful categories so as to bring out their essential pattern and data were analyzed in accordance with the points of discussions put on the interview guides.

In this particular study, the researcher was employed interpretive analysis through transcription and text management (interpreting the participant's communication in to a written

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form with no change of meaning and as direct quote). The raw data gathered from the field study through the field notes and the tape records was carefully transcribed word by word followed by putting code/pseudo name directly into the transcribed texts of the field notes and the respondents' answers under each topic. Themes of the transcribed texts were also organized in accordance with the points of discussion on the interview guides. As part of the data interpretation and analysis process, the researcher was also consider real quotes from the interviews with the participants that denote what the researcher thinks are important topics in the data. While interpreting and analyzing data, the researcher was tried to avoid subjectivity and involvement with the stories. Gibbs (2007) define qualitative data analysis as a process of transformation of collected qualitative data, done by means of analytic procedures, into a clear, understandable, insightful, trustworthy and even original analysis.

### **3.1.8. Trust worthiness and Data Quality Assurance**

Qualitative researchers have agreed to ensure that data trustworthiness, whether the data's has obtained from direct observations, focus groups, or interviews, is evidenced by transferability, dependability, conformability and credibility (Lincoln & Guba, 1985). Transferability refers to evidence supporting findings to other contexts across different participants, groups, situations, and so forth and dependability is the claim that similar findings would be obtained if the study were repeated while conformability refers to objectivity /neutrality/ and the control of researcher bias. On the other hand credibility refers to the believability of the findings and is enhanced by evidence.

In this study, the quality assurance criterion (transferability, dependability, conformability, and credibility) ensured by the following strategies. Spending longer time in the field, triangulating the data (using the primary and secondary data sources), using probing

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questions, maintaining data coherence during analysis, observing the participants during the FGD discussion, Peer examination (using an external reviewer) and evaluating the research by individual who is a professional and familiar to the topic. Besides; a good rapport building in the first contact and then forth supported the researcher to observe and interact with the participants easily to assure the data quality.

### **3.1.9. Ethical Considerations**

Prior to the data collection the researcher has asked a supporting letter from AAU school of social work to get the necessary data from whom they concerned. Besides, during the time of data collection, the researcher was asked a written permission from community social service workers of HIDO who are regularly working on the site to provide them a care and support services. After permission had granted, the researcher was also seek consent from the research participants. The participants were asked whether or not they are willing to participate in the research. The researcher were respect the participants freedom to choose to participate in the research or not as well as to choose to discontinue participation at any time. Furthermore, the researcher was provided, to the participants pertinent information about the planned research including the purpose of the research, the likely benefits of the research, the procedures to be undertaken, the duration, and the right of the participants withdrawn their consent at any time. When data were collected and presented the privacy of the research participants was respected and information gained from them was kept confidential and anonymous manner.

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**Chapter four****4. 1. Data presentation****4.1.1. Demographic Characteristics of the research participant**

As indicated in the objectives of the study, the first characteristics of the research participants' examined in the study were sex, age, and marital status, level of education, religion and ethnic group. Socio-demographic background of OVCs for ART adherence and their care givers have a great challenge on the development and well-being of the children. The detailed information with regard to each variable is described as follows.

*Table4.1. Demographic Characteristics of the research participants*

<i>Pseudo name</i>	<i>Sex</i>	<i>Age</i>	<i>Educatio n status</i>	<i>OVC status</i>	<i>Religion</i>	<i>Disclosed by their families</i>
Jemila	F	14	Grade 7	Single orphan	Orthodox	No
<i>Eyasu</i>	M	15	Grade 8	Double Orphan	Orthodox	Yes
Rahel	F	16	Grade 9	Single Orphan	Protestant	Yes
<i>Ayalew</i>	M	16	Grade 9	Single orphan	Orthodox	Yes
Kidist	F	15	Grade 8	Double Orphan	Muslim	Yes
Mekonen	M	16	Grade 8	Single Orphan	Orthodox	No
Emebet	F	17	College	Double Orphan	Orthodox	Yes
Abebaw	M	15	Grade 5	Single orphan	Protestant	Yes

As we observed in the above table, six of the participants were disclosed their HIV status household to himself /herself and Knew their HIV status clearly. However, the rest two of the participants didn't disclose their HIV by their household's rather they herd from others.

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### **4.1.1.1. Age**

As indicated in the above table, one of the demographic characteristic examined from OVCs for ART adherence was the age of the child which has great challenge on OVCS for ART adherence. Accordingly, the age of all of the children's participated in the study was 14-17 years. The researcher has also asked the participants to indicate their HIV status: weather their households properly disclosed their HIV status to himself or herself or not. Two of the participants' (Mekonen and Jemila) clearly explained that they didn't heard from their parents rather they heard from others whereas, the rest of the six OVCs know their HIV Status by their respective household's. However, studies advised that; children have better to know their HIV status based on their maturity level and the caregivers themselves has better to disclose the status of the children as per their maturity and age (Hontelez et al., 2010).

### **4.1.1.2. Education**

Concerning their educational level, participants were asked to indicate the current level of their educational attainment. Accordingly, two of the participants (Ayalew and Rahel) were in grade 9, three of them (Eyuael, Kidist and Mekonen) were in grade eight, the other two participants (Jemila and Emebet) were in grade 7 and college respectively. While, the rest one research participant (Abebaw) was a grade 5 student.

### **4.1.2. Religion**

With regard to their religious background, research participants were also asked to identify their affiliation towards a given religion. As a result, five of the participants are orthodox, two of them are Protestants and the rest one is Muslim. As the research participants indicated that, in most cases, HIV positive people were interrupt their ART due to religion

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matters like went to holy water and pray in the church to relief and resilience that may help PLWHA to overcome their challenging situations.

One of the research participants Emebet was described that:

*I interrupted my ART more than three times. The cause of my ART interruption was family disturbance, discomfort, going to holy water, low support and understanding. As a result I went to the monastery and I stayed until 9: 00 o'clock without taking the ART to drink the holly water before anything else.*

### **4.1.3. Participants' ART status and the challenges of OVCs related with ART**

#### **4.1.3.1. Participants' ART status**

As the research participants were explained, currently all the participants had taking their Art. Among the eight research participants five of the research participants could take their ART outside their resident areas and the rest three were taking in their residents. Regarding to the time started their ART, the highest is 16 year's back and the lowest is 4 years. While, in relation to the ART Adherence, three of them were interrupt their ART in the last one year; two of them were not maintained their regular time to take it and the rest three participants took their ART properly and timely.

One of the research participants Ayalew stated that:

*I am a 16 years old, single orphan, HIV positive child lives with my mother in Addis Ababa. I know my HIV status in my early child hood from my mother. In my early child hood I was sacked too and my CD4 content were to low. I am started the ART in 2003 E.C. However, I and my families are not disclosed my HIV status for the community rather for those people who have*

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*similar status in the neighborhood. Previously, me and my mother had been took our ART at St. Paulo's hospital, which is out of our local area. Due to the fear of stigma and discrimination my mother and I are taking our ART in AHF around megenagna, which is too far from the previous one.*

The other research participants Rahel also described as:

*I am a 16 years old, HIV positive, single orphan child living with my mother in Addis Ababa. I am a protestant religion follower and I am a happy, relaxed, fast and communicative with other people. I know my HIV status during my infant time. When the mother was going to hospital for the post natal care, it was that time I took VCT and my result is positive. Currently, both my mother and I had taking the ART drug from Yekakit Hospital.*

Concerning to the cause of HIV infection, four of the OVC are transmitted from mother to child, three of them were not clearly known their causes and one of us was due to blood contamination in the time of care and support.

One of the research participant's emebet indicated that:

*I am a 17 years old double orphan, HIV positive child. I am a first year college student. I have one younger sister and two brothers. My behavior is simply disturbed and boarded. My relationship with another people was not as such good. In most cases, I easily irritate and upset in communicating with others. In my ten years, I came to Addis Ababa with my aunt. After I came, I was sacked. As a result, together with my aunt they went to Yekatik Hospital and it was that time I know my HIV status. Still now, I don't know the real case how I caught by HIV. My mother, who lives in rural area, was an HIV positive. She interrupts her ART and was sacked*

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*highly. During that time, I was given different support to my mother with low care and understanding.*

### **4.1.3.2. The challenges of OVCs related with ART**

The research participants have described the followings as a challenge for OVCs for ART adherence: disclosure issue, lack of clear communication, loss of love and affection, stigma and discrimination, problem of basic needs, problem of scholastic materials, problem of adult care giver (for double orphan children), loss of proper care and support, absence of follow up, known the disease lately, opportunistic infections, absence of affinity group, fear about shortage may happen for ART drug, imputation of the community, lack of detailed understanding about HIV and ART, interruption of ART drug and irregular time taking, were the most common.

The research participant jemila described that:

*When I am 10 years old I sacked repeatedly I had been started to take the ART. During that time, I faced different discomforts and signs (headache, itch, dandruff, problem of ear, loss of appetite, and distress) up to two years. I know my HIV status because of my female friend's when they were supported by an organization. Besides my mother, I have one brother and sister that provided me different support and remind my ART. Even though, my mother and I had been taking the ART in the same place, St. Paulos hospital, they took in different time of appointment. Moreover, I have no clear information about the ART drug, how I am taking, for how long it takes and for what purpose. Including my family, I don't want to disclose our status because of fear of stigma and discrimination.*

The other research participant Emebet also explained that:

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*I am 17 years old double orphan, HIV positive, child. I was living many years without ART and I know the disease lately which created great challenges on my eye. Besides, I am also interrupted my ART more than three times due to went to holy water, family disturbance and discomfort, ill-tempered behavior, low support and understanding by her aunt. In order to minimize and avoid stigma and discrimination, I had limiting my communication from my friends, the neighbors and the person knows me. I don't want to disclose my HIV status for other people except for my HIV positive friends and aunt.*

Another research participant Eyasu also stated that:

*I am 15 years old, double orphan, HIV positive child. I was born in Oromiya called Yigachefee and now living in Addis Ababa. I have had faced many uncomfortable conditions starting to know my HIV status in 2000 E.C. I come to Addis Ababa with my uncle and I sacked for three months long. Since my start, I had taking the ART for 11 years and also interrupted the ART drug for many times. The cause for my interrupt was ignorance of my uncle due to education related conflict. As a result, I left the home and started to live and work on the Street of kolfee for 6 months. Due to the joint effort of an organization called HIDO and WCAO I came to back the previous resident place and adjusted to living with a woman that have little blood relationship to me.*

Still another research participant, Mekonon described that:

*I am 16 years old, single orphan, HIV positive child lives with my father in Addis Ababa. My mother was died due to HIV related case. I know my HIV positive status through observation when my father was taking the ART. Lately, when I come to being as matured, at the age of 12 years, I suspected that, the tablet I had taking by the order of my father is an ART drug. My*

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*father didn't disclose my HIV status and how long it had been stayed. Due to the delay, I started ART, I faced many side effects including lisp and sight problem. However, still the exact cause of the problem of lisp and sight was not identified. In addition to these, I had been also faced by another infection such as: stomach, headache, ear, heart, and different opportunistic infection which are challenging in my day to day life.*

### **4.1.4. The needs of OVC on ART adherence**

#### **4.1.4.1. The need of access to basic needs**

As the research participants and case managers stated that, most of the children categorized as OVC have no/low access to basic needs such as food, shelter and clothes. Majority of these OVC on ART lives with single parents, poor and the sick relatives/guardians who did not able to meet these needs. Whatever the content of the food, they have a great challenge to get even three meals a day. They have no regular or sustainable sources of income to sustain their lives for children who have no guardians. On the other hand; they also need easily accessed facilities and functional system that has available in there, neighborhood and community. As a result, children who lost their parents in one or another means and lives with HIV needs close relatives to full fill their basic needs before they are forced to go to on the street in seeking food or other necessities.

*I am 15 years old, double orphan, HIV positive child. I am living in Addis Ababa with woman that has little blood relationship to me. I need to get my family relatives and love and affection in advance. I also need to a full responsible body to fulfill my basic needs .I was stared a street life before I came back.*

#### **4.1.4.2. The need of special concern and privilege**

Creating detailed awareness having especial attention and privileges were important for HIV positive people to maximize their roles, to increase their participation and maintain the ART adherence. The, families, the neighbor, the community, and the government would facilitate access for services and take their efforts to support the OVCs with full protection. Moreover, OVCs on ART need fertile environment to scale up their talents, skills and potentials in their localities in order to develop their confidence and resilience.

As one of the KII-4 described that:

*To meet the needs the OVCs: the individuals, the communities and the government bodies maintain the privileged the OVC on ART. Besides, providing the short term trainings like: life skill training, hygiene and sanitation training, and nutrition and health education very essential to be aware more about themselves and a means to meet their needs. The trainings were based on their age between 14-17 years. Besides, the NGOs, who are working, in the Sub city, about HIV/AIDS, income generating sills, health and psychosocial support and had given priority for the OVCs.*

#### **4.1.4.3. The need of primary care giver**

Parents have the responsibility to shape the behavior of children when they grow up in a family. As a result OVC need primary care givers that act as for the children like a biological parents. A long life treatment, ART also needs proper follow up and reminder with proper care.

Discussant1 stated the need of HIV positive OVCs on ART as follows:

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*“Children who are orphan and lives on the street have many needs. As part of many other primaries one is having an adult care giver who monitor and reminds their time to take the ART drug on time.”*

### **4.1.4.4. The need of love and affection**

ART primarily needs of the OVC were the need to have love and affection from their parents/care givers. Especially the double orphan children have had high desire to have love and affection from their primary givers and equal treatment like their own children.

*I am a 17 years old double orphan, HIV positive child. I really need love and affection since I lost my parents once and at all. I don't know how to live positively with others I simply disturbed and boarded. My relationship with another people was not as such good*

### **4.1.4.5. The need of social support and affinity group**

As the research participant's explained that; the involvement and role of the community was not consistent and didn't similar for all individuals. Some of the peoples are emphatic and supportive while the others did not care about the OVCs and PLWHA. As a result, in order to be at equal foot the Government and other concerned actors should work for awareness rising to provide proper care and support for the children's.

*As one of the House hold discussantsHH4 stated that:*

*There are minimal supports in the community and from the government which didn't answer the needs of many OVC living in a challenging situation. Even the supports came with our names were not reached for the HIV positive and the vulnerable OVCs properly.*

#### **4.1.5. Coping strategies of OVC on ART Adherence**

Regarding to the coping strategies the research participants were stated that:

**4.1.5. 1. Participate in recreational activities:** Talking and playing with similar status peers, watching TV, having enough sleep, walking on the street with their friends, loved ones and lonely, went to wholly water and church, praying on the church, listening to music, being feel happy, and reading different book and bible, Playing (football, table tense, mobile gams), looking films, visiting (historical places, parks and, green areas).

**4.1.5.2. Mobilize a support system:** straighten and connect with others, especially those who may have shared the stressful event and talk about the traumatic experience with empathic listeners helped the OVC on ART to consider their problem is not unique from others. They also have real life experience from others and shared their problems without fear of stigma and discrimination. Some people also cry and the other also doing hard exercise like jogging, aerobics, bicycling and walking.

As one of the research participants Emebet explained that:

*I am 17 years old double orphan, HIV positive, child. I had limiting my communication from my friends, the neighbors and the person knows me. I don't want to disclose my HIV status for other people except for my HIV positive friends and aunt. Taking with PLWHA helps to me a lot to be relaxed and seen my case as simple especially such diseases like cancer and diabetes which is currently dangerous for many once.*

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**4.1.5.3. Getting awareness and skill:** having a comprehensive and detailed understanding for ART, minimizing stigma and discrimination, having especial consideration and proper legal protection, establishing and strengthen positive affinity group at health center level, provision of life skill education training, getting income generating skill training, hygiene and sanitation education, getting proper counseling and getting an adult follow up.

As one of the KII-3 case manager stated that:

*The OVC who lives with their single parent have better to cope up their problems than those for double orphan children. They easily shared their emotions to their families once they disclosed their cases. While the double orphan children's are very happy when I share my experience about the ART and the conditions which was worsen before now. Especially the OVCs who have got life skill training by the NGOs have better to cope up their worries, challenges and the drug related effects positively and they share to me what they faced and how they cope up it.*

**4.1.5.4. Access to loan to get material, financial and social support:** access to loan and cash transfer, provision of cash money, school feeding, getting love and affection ,access to kebele house and government funding ,access to free medical service, having, familial, community, institutional, NGO and government support.

Regard to the coping strategies to improve the OVCs on ART adherence discussants (1, 3, 6, and 8) stated the followings:

- Facilitate conditions to be acceptable by the community
- Educate the OVCs to be self-confident by themselves, and protect themselves and others from any risk

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- Establish and strength a follow up strategies at home to home level and remind whether they take the ART or not.
- Alleviate lone ness attitude and link/ establish HIV positive affiliation groups together.

On the other hand discussants (2, 4, 5, and 7) stated the following coping Strategies to improve the OVCs ART adherence:

- Strengthen free communication and openness to the families, the neighbors and communities and Share ideas freely and frankly every where
- Establish HIV positive people association and club in the community level
- Established children and youth, adult club /affiliation group/ in all hospitals and health centers which is started now Yekatit 12, Zewuditu and Alert hospital.
- Established and strengthen the systems of a care and support program for HIV positive OVCs.

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**4.1.6. FGD of OVCs on ART***Table 4.2 back ground information for OVCs FGD*

<i>Discussants Pseudo name</i>	<i>Sex</i>	<i>Age</i>	<i>Education</i>	<i>Place of birth</i>	<i>OVC status</i>	<i>Religion</i>	<i>HIV status</i>
Discussant -1	F	14	Grade 7	Addis Ababa	Single orphan	Orthodox	Positive
Discussant -2	M	15	Grade 8	Ambo	Double Orphan	Orthodox	Positive
Discussant- 3	F	16	Grade 9	Addis Ababa	Single Orphan	protestant	Positive
Discussant- 4	M	16	Grade 9	Addis Ababa	Single orphan	Orthodox	Positive
Discussant- 5	F	15	Grade 8	Gondar	Double Orphan	Muslim	Positive
Discussant -6	M	16	Grade 8	Addis Ababa	Single Orphan	Orthodox	Positive
Discussant- 7	F	17	College	Adama	Double Orphan	Orthodox	Positive
Discussant- 8	M	15	Grade 5	Addis Ababa	Single orphan	Protestant	Positive

After the researcher and the note taker introduce themselves first, and the researcher was provided FGD guide orientation, the participants were selected one person as a moderator, to lead the group. Regarding to the ART awareness and understanding, almost all the discussant had similar level of understanding. All of them had aware about ART is a lifelong drug. However, only four of the discussants, (discussant 2, 3, 4, 6) have clearly understood that ART is a drug that increases the human immune system /CD4 content/ and suppressed the viral. Besides it also enables the body to protect the opportunistic infections Of HIV virus. While, the rest of

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four discussants (discussant 1, 5, 7 and 8) simply understood ART are a lifelong drug and no more awareness beyond this.

As discussant 4 presented in awareness on the ART drug as follows:

*ART adherence helps to increase the CD4 content in our body and suppress the viral load.*

*When the person takes the ART drug in a proper manner, timely, without interruption, the ART drug helps to minimize the side effects of many diseases related to opportunistic infections which attack the individual body system.*

The other discussant 6 also described as:

*ART is a lifelong drug that enables the body to protect other diseases which mostly known as side effect of ART drug. When we take the ART properly it increases our CD4 content, to protect the opportunistic infections. She also explained that, AIDS like mucus which is caused by virus and its main side effect differs from person to person. The most come side effect for me is that “yesamiba michi and almaz balechira” were the common one.*

On the other hand, regarding the different challenges of HIV positive OVCs on ART; the loss of parents, absence of proper care and support, stigma and discrimination, worthlessness, boredom, stress, headache, in appropriate disclosure, age, absence of adult care giver, and problem of basic needs were the most challenging aspects in the children’s life to maintain the ART adherence.

As discussant 2 described as:

*The losses of parents are the primary cause for the interruption of ART drug. She believed that, even though there are many challenges even with the presence of parents the loss of love and*

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*affection from a parent by itself leads to being worthless and senseless for life. If parents are alive to the front whatever the challenges, whether simple or difficult, children's were tried to solve it in order to satisfy the families and got the moral reward.*

Another discussant 4 in the study also stated as:

*The loss of parents is the main challenge for the interruption of ART, especially for double orphan challenges. Even though, the supports had given by their relatives the child loss a sense of belongingness. Besides, if the relatives have their own child they did not seen just like their own child. The OVC lack this big opportunity. Moreover, the community was not also provided proper care and support rather they stigmatized and blamed them.*

### **4.1.7. Households FGD data presentation**

The house holds discussants were purposively selected and they are the care givers of the OVC. The main aim was obtaining firsthand information and how caregivers understand the challenges of the OVC and the adverse impact of the disease. In addition, they described their challenges in raring the OVC on ART and share the possible coping strategies to make an appropriate measure.

**4.1.7. 1. Demographic characteristics of House hold FGD***Table4.3 back ground information for Households FGD*

<i>Pseud name</i>	<i>Sex</i>	<i>Age</i>	<i>Employment</i>	<i>Education</i>	<i>Religion</i>	<i>Place of resident</i>
Discussant HH1	F	50	Employed	Grade 9	Orthodox	Addis Ababa
Discussant HH2	F	48	Not employed	Grade 9	Muslim	Addis Ababa
Discussant HH3	F	70	Not employed	Illiterate	Orthodox	Addis Ababa
Discussant HH4	F	49	Not employed	Grade 6	protestant	Addis Ababa
Discussant HH5	M	45	Employed	Grade 7	Orthodox	Addis Ababa
Discussant HH6	F	42	Not employed	Grade 6	Orthodox	Addis Ababa
Discussant HH7	F	47	Not employed	Only read and right	Orthodox	Addis Ababa
Discussant HH8	F	46	Employed	Grade 9	protestant	Addis Ababa

With regard to the discussants educational status three of the discussants (HH1, HH2 and HH 8) were in grade 9, two of the discussants (HH4 and HH6) were in grade 6, and the remaining three discussants were in grade 7 (HH5), only read and write (HH7) and illiterate(HH3). In relation to employment, only three of the discussants (HH1, HH5 and HH8) had employed while the other five discussants were not employed. Regarding to the religious affiliation, five of the discussants are Orthodox follower, two of them are protestant and the other one are Muslim. Concerning to their current resident all of them is living in Addis Ababa.

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Regarding, the detailed awareness about ART adherence, currently, all the discussants (HH1, HH2, HH3, HH4, HH5, HH6, HH7 and HH8) were aware about ART adherence and are taking their ART properly. However, in the previous years (years before one years and forth) all the discussant's except two them (HH6 and HH8) had faced different challenges. On the other hand, still two of the discussants (HH5 and HH6) are faced challenges about the issue of disclosed to their children's.

As discussant HH1 stated that:

*Still the awareness and understanding of the community about the HIV/AIDS and ART has low. As a result, there is stigma and discrimination even in the family level. For example; during the client's time of test in health center, there was a woman she knows the client's HIV test result and disseminates the information immediately without her consent. As a result of the fear stigma and discrimination the clients had hidden her for one month inside the home with no contact for others.*

The other discussants HH2 also described as:

*When her husband was died she was pregnant of her last child. During that time, the wife did not know her HIV status until she delivered. She has no awareness about ART and how to protect mother to child transmission like now. After she delivered she gave the child for an organization because she knew that the child was HIV positive. When the child was raring and the organization was closed, the child returns back to the home and rearing together with her families.*

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Concerning to the major challenges OVCs encountered for ART adherence: the issue of disclosure, stigma and discrimination, economic and psychological problem, the absence of adult care giver, side effects of ART, problem of basic needs, and blaming their families were the most one.

As the discussant's HH2 explained that:

*Still now, the child asked, her mother repeatedly, why she only being HIV positive except of her sisters and brothers. However, the mother was not clearly disclosed how the child is infected by HIV/AIDS. The reason was that the mother had still in great grief because of her cause ness mother to child HIV transmission.*

The other discussant HH3 also described that:

*Is a 70 years old grandmother that has rearing her daughter's child. The challenge faced was, the family is extremely poor and there were no relatives here in Addis Ababa because our families are found in Gondar at Gorgora. Besides, when the child finished her ART drug she was worried highly because the child feared that the ART may not also be available in the health center. Moreover, when the child was taking the ART drug there are many side effects, like headache, itch, problem of ear, and dandruff. Furthermore, when grandmother was sacked the child was also tensioned. Beyond these, before, her mother's died and received her daughters, her sister's husband were discriminated them because of her child and he did not willing even to share the toilet.*

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**4.1.8. Key informant Interview/KII/****4.1.8.1. Demographic characteristics of KII**

Regarding the Key informant's educational status; two of them had BSC degree, and the other two have diploma and the rest one had completed grade 12.

*Table 4.4 back ground information for KII FGD*

<i>Code</i>	<i>sex</i>	<i>Age</i>	<i>Educational Status</i>	<i>Occupation</i>	<i>Marital status</i>	<i>Religion</i>
KII-1	M	49	BSC degree	Gulele sub city HAPCO manager	Married	Orthodox Christian
KII-2	F	42	Grade 12	Case manager	Widowed	Orthodox Christian
KII-3	F	34	Diploma	Case manager	Divorced	Orthodox Christian
KII-4	M	30	BSC degree	Disease protection and HIV/AIDS focal person	Single	Orthodox Christian
KII-5	F	28	Diploma	Referral link desk officer/ART counselor/	Single	Orthodox Christian

Regarding the major challenges that HIV positive people encounter in ART adherence and, the OVCs in particular encountered were: problem of housing, problem of identification card, economic problem (particularly a startup capital), stigma and discrimination, challenge of medical examination for those works on restaurant and food, unemployment, work load for those who leads their life by washing cloth, problem of accepting the diseases and seen as an evil, problem of side effects, inappropriate intake of the ART, interruption, and, disclosure issues were the most common.

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KII-2 stated that:

*“People who have no Identification card did not have access for different services even to be a member of HIV association and having free kebele house in their resident. Besides, there housing problem and identification card, they did not get a startup capital to start their local businesses that are given for HIV positive people and low income”.*

KII-3 also described that:

*The community stigmatized and discriminated HIV positive people especially regarding to home rent. Once they know the HIV positive status people, who rent their home, the owner of the house started to discriminate systematically. They said that, after three months my son /daughter come from abroad or another area, as a result, you better search another home because I need it mine.*

On the other hand, the challenges of OVCs on ART were much more complicated such as: vomiting, issue of disclosure, itch, absence of adult care giver, low care and follow-up, absence of reminder, boredom of the drug due to its long life, worthlessness and stress, absence of care and support, living and working on street, opportunistic infection, lack of nutritious food, low span of attention for the ART, isolation and low understanding and knowhow for the ART in general were common once.

KII-2 is one of the members of KII and she described that:

*As the case manager explained that, within in the house hold that are four HIV positive family members and took their ART. However, only the younger one that has 7 years old has interrupted her ART many times due to low care and support, low understanding and knowhow as well as boredom. On the other hand, in the other house hold, a child who was stopped his*

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*ART for three consecutive years the family did not have any information for child's ART interruption. The family believed that the child was taking his ART meaning there were no follow-up, care and support.*

KII-3 is the other members of KII and she also stated that:

*Due to the economic problem there is a child in the community who is rearing by her grandmother and swallowed her ART drug after eating enjera by paper ('enjera be metimita belita ye ART medihanit yemitwosed lij alechi'). Besides, they were children's living on the St. Rufael who lives and work on the street also faced a great challenge because of the problem of shelter. As a result, their ART drug was spoiled by rain and sun.*

Regarding to the challenges happen between the service givers and the service users all of KII (KII-1, 2, 3, 4, and KII-5) were described that: there was good relationship and emphatic attitude between the service givers and the clients. However, the service users were not used their ART timely and properly. In addition, there was a problem with their time of appointment. Moreover, they mostly lost their drug; due to different reasons such as: going to a holy water, church, move to another distant area and forget. Furthermore, in most times, HIV positive people prefer to take their ART outside their local place which is not convenient for follow-up.

KII -1 is one of the KII and he stated that:

*Concerning to the relationship between the service providers and the clients there was no problem. In all the ten health centers of Gulele sub city, health professional was trying to solve the client's present problem. They provided a home to home follow up for HIV positive people to maintain their ART adherence. In this case, the problem mainly faced was, clients in most cases, were not come back on their appointed time and they sometimes missed it totally.*

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Focusing for the roles of the individuals had developing their awareness and interest to know their HIV status and if Positive start the ART drug immediately. At the community level, communities strengthen the care and support program and facilitating ways of creating awareness like coffee ceremony and discussion program. In addition, the community has started a support to the OVCs in a sustainable manner. At the government level, government creates detailed awareness using the media coverage. Besides, in addition to the proper fulfillment of test kit, adjusting VCT professionals working in their free time like Saturday and Sunday is also good for Children's who are attending their school and want to test at the weekend. Moreover, properly function and mainstreaming the HIV/AIDS program for all sectors also good and which is expected from the government. Furthermore, the different NGOs signed and working in the sub city had been working closely, in an integrated and collaborated manner, one to the other and with the government. Generally, when it looks in the context of time the case of Addis Ababa, to meet the ART adherence, are too challenging, even though some regions were achieved.

KII-3 is one of the KII she explained that:

*The community shall be better to provide proper care and support by avoiding stigma and discrimination. In addition, educating the community in advance about comprehensive HIV education and HIV/AIDS related goal has great role. For example; in Selam Health center there was five children's who are supported by the health center staff contribution 360 birr for each OVCs per monthly. Likewise, government should take the role of creating detailed awareness, proper media coverage, provision and facilitation of different services like world food program and school feeding. Besides, the government strengthens the existing system and mainstreaming program through facilitating loan and cash support which is free from interest rate is a good method to meet the three 90's HIV/AIDS goal.*

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KII-4 is one of the KII and she described that:

*To maintain the ART adherence first individuals should be aware enough about HIV/AIDs and ART. Once the status was known, the individual has decided to started ART immediately and take continuously. Besides, link the HIV positive to the case managers and creating favorable condition was so important to maintain their ART adherence.*

Regarding to support and participation of the community to meet the needs of OVC for ART adherence it was not as such enough and good. Many things had been remaining including creating comprehensive and detailed understanding; strengthen referral systems, linkage and integration for all concerned bodies especially, for the religious leader.

KII-3 is one of the KII and she described that:

*To strengthen the ART adherence a comprehensive HIV/ AIDS education and ART adherence related orientations shall be good to provide for all concerned bodes especially for the religions leader's and the church. Because, in most cases, people interrupt their ART related with religious aspects. Therefore, the roles of religious leaders are too great.*

KII-1 is the other KII and he stated that:

*Regarding the involvement and contribution of the community's to support the OVC on ART, Gulele sub city HAPCO were given awareness program for Idirs, shemachochi, NGOs, and for all the concerned government sectors. As a result, 120 HIV positive children's (56 males and 64 females) were supported in the sub city from 360 to 700 birr/ month. Besides of the cash support, "ididrs" and "shemashochi" had provided uniform and educational material support for the OVCS every year. However, previously there was world food program in the sub city and during*

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*at that time there was 1245 children supported in the sub city. Even though, the beginning of the communities and government sector's initiations are good it did not enough as compared with the number of OVCs on ART.*

## **Chapter Five**

### **5.1. Discussion**

In this section, the researcher has tried to associate the finding of the research with the previous researches based on the research question as themes. This research has three major themes. The first one is participants' ART status and the challenges of OVC for ART adherence, the second is the needs of OVC on ART adherence and the third is the coping strategies of OVC on ART.

Besides, the finding of this study about challenges of OVCs for ART adherence was viewed from four dimensions: implication of the study for social work education, practice, research, and policy in general, and the Challenges of OVCs for ART adherence in particular. Since the main method of data collection was in-depth interview, FGD and Key informant interview the following discussion is given based on the research questions.

#### **5.1.1. The challenges of the OVC's on ART adherence**

Regarding this issues, research participants were described many different and similar challenges based on their real life situation and their observation what was happened for the other people including their families or relatives.

##### **5.1.1.1. The issue of disclosure**

One of this research finding of this study explained that, the challenge faced OVCs for ART was the issue of disclosure. Their parents were not described how they caught by HIV /AIDS and taking the ART. The main reasons to be hiding the issues were the age of the child. However, even those children's who are matured and able to hear their HIV status were not informed properly. Besides, the children have not clear information about the ART drug and how

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long they would be taking. Moreover, they didn't also understand why they are taking the ART and the side effects faced. Furthermore, the children were confused about why their parents did not communicate freely about their issues. As the house hold discussants described that, the parents were not interested to tell the cause was "I" as a proud thing, for those OVC who infected by mother to child transmission. Because, the family themselves were in a great grieve, because of their mistakes how much their child had impacted in his/ her long life. Moreover, the households were feared the stigma and discrimination comes from others (if the child shared to others unconsciously) and it becomes the child worried and hurtled too. Furthermore, the understanding and the knowledge of the house holds about ART was low. Therefore, the finding of this study is consistent with the other research findings.

A study conducted in this issue in, Bahir Dar, North West Ethiopia. described that: disclosure was also delayed because caregivers believed that they lacked disclosure skills and relied on the support of the health care providers to disclose the HIV positive status to their children (Alemu et al., 2013). Establishing improved and focused counseling services for caregivers through professionally skilled counselors so that caregivers could have a responsibility to decide on the proper time to disclose, and formation and strengthening of children's support groups will help children to know about HIV/AIDS and allow them discuss more about the barriers of disclosure (Alemu et al., 2013). The other international Journal of MCH and AIDS study described that, 60% of the children studied were not aware of the reasons why they were frequently visiting the health services since their HIV status had not been disclosed to them by their primary care givers. The children believed that they visited the hospital for minor illnesses such as flu, headaches, and cough. This implies that some of the

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children would grow up and become sexually active without knowledge of their HIV status and will thus not reveal that to their partners (Monyau et al., 2012).

### **5.1.1.2. The issue of stigma and discrimination**

The other finding of this study was the issue of stigma and discrimination. As participants stated that; the way stigma and discrimination manifested currently were changed from the past and it was conducted in a systematical manners. Once the community knows the HIV status of a particular child, they were informed to their children's in order to limit their contact and playing together. In addition, the community did not provide proper guidance, care and support rather they suction their lips which is adapted culturally and no more value added for the children and their care givers life. Moreover, households did not get a house to be rented as the result of stigma and discrimination. If they were rented the house before, the owner of the house informed them to leave it within three months by imputing my son will come soon from abroad and the house will needed for that purpose.

A study carried on this issues in Ethiopia described that; stigma and discrimination have taken their toll in Ethiopia not only at the work place, in housing, health facilities, schools, and in family and personal relationships but also in the medical services, discouraging people from being tested for HIV (Kloos & Mariam, 2007). Another study conducted in Bahir Dar also explained that; the lower prevalence of disclosure in developing countries as compared to developed countries might be due to caregivers' fear of stigma and discrimination and believed that their children would be isolated by their friends at school and in the community, and fear of negative consequences for the child (Alemu et al., 2013). Caregivers were also lack knowledge and skills on how to approach/inform their HIV infected children about their HIV diagnosis (Alemu et al., 2013).

### 5.1.1.3. The challenge of basic needs

The other challenges of OVCs for ART adherence was the challenge of basic needs. Even though, having basic needs is a base for children's development, the access and fulfillment of their needs as a child was in great challenge due to the loss of their parents, deep rooted poverty and the ART drug. Even for those children's who have single parents (female in most cases) their need has in question related with the ART drug. Most of these reach participants (five of them in number) were supported by school feeding while the rest three of them didn't get any support. Even though, the health professionals and doctors were advised to take nutritious food, for OVCs on ART, the economic challenge created a great impact even in to their survival. As one of the case managers explained that; "there is child took her ART enjera with paper only. In Amharic language, "Derek enjera be mitimita belita ART yemiwosdi lij alechi. She said that, you can imagine how much their problem was challenging to maintain the ART adherence". Regarding to sex, among the eight households seven of them were females and the rest one is male. On the other hand, concerning to their educational status six of the households was from grade 6 to 9, and the rest two households could only read and write and illiterate.

A study conducted in this issue stated that: Care givers had the lack of access to adequate food and nutrition as a major challenge affecting the children ART adherence. It was found that the children on ART who were not having adequate access to food and nutrition were not coping well with the therapy though some of them ended up begging for food and avoiding the ARV drugs (Monyau et al., 2012). Another study also described that; HIV prevention programs among poor people may be compromised by their stigma and discrimination from many HIV prevention programs and their irrelevancy to meeting basic needs. Unmarried Ethiopian youth and the

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swelling numbers of street children, for example, have no access to VCT services due to socioeconomic barriers (Kloos & Mariam, 2007).

### **5.1.1.4. Lack of coordination and integration of the supports**

The other challenges of OVCs on ART was lack of coordination and integration of the supports: Even though, there are organizations providing various supports and services, the services and the supports being provided are not integrated and lack coordination. The supports being made are mainly focused on provision of educational materials. However, the OVC not only need educational materials and uniforms but also need feeding support either in kind or in cash. As the OVCs FGD and house hold discussants stated that, even the educational material support itself could not reach for all needy children in time.

ART program requires the highest degree of coordination and integration to succeed in a health system with very little or no previous experience in this area. Strong information management and communication will serve as a backbone for this program (FHAPCO, 2007).

### **5.1.1.5. Low understanding and awareness about HIV/AIDS and ART**

The other finding of this study was the presence of low understanding and awareness about HIV/AIDS in general and the ART adherence in particular. Even though, almost all people heard about HIV/AIDS, people who have comprehensive, detailed knowledge and understanding were few in number. As compared to the rural ones the urban dwellers are expected to have better understanding and know how about HIV/AIDS. However, Addis Ababa is the second HIV exposed city with 3.2 % of HIV yield next to Gambella with 4.8% HIV rate. Thus, the case of Addis Ababa needs further elaboration and justification. Anyway, it had a clear indication for the absence of comprehensive knowledge and understanding about ART adherence

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in particular and HIV /AIDS in general. As the research participants stated that; from the eight study participants, three of them were interrupt their ART in the last one year; two of them were not also maintained their regular time to take their ART. In this regard the finding of the study is consistent with the others.

A study conducted in Nigeria revealed that; there has been a significant urban-rural gap in HIV/AIDS knowledge of senior secondary students. Overall, urban students had significantly higher knowledge mean scores than the rural students (Ayodele & Ayodele, 2016) . The other challenges faced here is that, most primary care givers were either too young or too old to take care for the children on ART such that they had problems adhering to hospital dates and times or monitoring the children on ART during their drug administration. As elsewhere, due to scarcity of data and limited awareness of HIV infection, especially in older children, the HIV epidemic among Ethiopian children appears neglected in national programs (children ART coverage is of only 12% in 2013) (Pegurri et al., 2015).

### **5.1.1.6. The Absence of love and Affection**

As many scholars are explained, the most important aspect for the children's development is the presence love and affection by their parents, relatives and the community. As a destiny, the OVCs on ART had little /no chance to get love and affection from their parents, even from their sister and brothers. Even those parents who are alive did not give proper love and affection to their children due to the burden of many psychological and social problems. Besides, they sometimes pass their time in order to search basic needs and mostly bedridden due to their HIV case. Particularly, for children's who lost both their parents, due to HIV/ AIDS, beyond of the loss of their parental love and affection, the challenge by itself had a multi-faceted impact on

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the children's life. As a result, the finding of this study is consistent with the study conducted in Ethiopia out of Addis Ababa.

A study conducted in Jimma by Berry and Guthrie about the situation of orphans and vulnerable children described that; Orphans and vulnerable children have been suffering from a lot of problems associated with these vulnerability factors. Some of the problems they face include hunger, lack of access to health and education, physical and psychological abuse, lack of love and affection and negative communities' attitude towards them (Berry and Guthrie, 2003). Because of these, orphans and vulnerable children require urgent basic needs and services supports that can be provided either within the community or institutionalized care (Gudina et al., 2014).

### **5.1.1.7. The side effects of ART Drug**

Although ART drug is a means for HIV positive people to live healthy and live a long, it had also different side effects unless it will take appropriately and started early. Besides, HIV /AIDS reduce the human immune system. As a result; OVCs on ART had faced different unnoticed and noticed opportunistic infection: such as lisping, headache, dandruff, stomach, itch, and problem of ear, eye, lung and others. Thus, the finding of this study had more or less similar result with the following studies:

A study conducted by Cao & Holmes described that: Antiretroviral drugs are known to produce short and long term side effects in some patients. Clinical follow up and frequency of monitoring depends on the ART regimen (Cao & Holmes, 2001). The other study also described stated that: the failure of adhering to the proper regimen of anti-retroviral (ARV) treatment carries three major consequences. First, the expected benefit of the treatment does not take place,

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the clinical situation worsens and mortality increases. Second, the irregularity of the intake of the ARVs brings new resistant strains of the virus, thus complicating its future control. Third, the interrupted or incomplete course of treatment wastes money and other resources that could otherwise have produced more cost-effective results in adherent patients (Mental Health and HIV/AIDS Basic Counselling Guidelines for Anti-retroviral (ARV) Therapy Programmes, 2005).

### **5.1.1.8. Inappropriate usage of the ART drug**

The other finding of this study was people who know their HIV status may not want to prefer to start the ART drug immediately. Even they had given counseling and get started they are not taken the drug timely and properly rather they prefer to go in to the church and monasteries. The reason for their refusal was they mostly considered the disease as evil and offence of the God. In this occasion patients prefer either to stop the ART drug or did not maintain the time.

A significant proportion of patient switching very late (with progressive accumulation of resistance mutations) and switching inappropriately (as the CD4+ count response may be poor in some patients, despite optimal biological suppression. We therefore advocate using the VL for making decisions regarding ART failure and the need to switch Virological (Meintjes et al., 2017)

### **5.1.2. The needs of OVC living with HIV/ AIDS**

#### **5.1.2.1. The need of access to basic needs**

Regarding to the basic needs, the OVCs on ART needs greater attentions to fulfill both their complementary and supplementary needs in their localities with a joint effort. As the research participants and case managers stated that, most of the children categorized as OVC

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have no/low access to basic needs such as food, shelter and clothes. Majority of these OVC on ART lives with single parents, poor and the sick relatives/guardians who did not able to meet these needs. Whatever the content of the food, they have a great challenge to get even three meals a day. They have no regular or sustainable sources of income to sustain their lives for children who have no guardians. On the other hand; they also need easily accessed facilities and functional system that has available in there, neighborhood and community. As a result, children who lost their parents in one or another means and lives with HIV needs close relatives to full fill their basic needs before they are forced to go to on the street in seeking food or other necessities.

Most health facilities lack basic requirements for curative and preventative treatments. This includes drugs and qualified doctors. This discourages most people against visiting them. All the identified challenges affect the quality of life of OVCs in terms of health, access to education, shelter and food (Nthenya & Mutuku, 2018b).

### **5.1.2.2. The need of primary care giver**

OVC need primary care givers that act as for the children like a biological parents. The primary role of families are providing care and protection as well as socializing and rearing of children. Parents have the responsibility to shape the behavior of children when they grow up in a family. However, nowadays because of HIV/AIDS many children become orphans and remain out of family protection or guardians. A long life treatment, ART also needs proper follow up and reminder with proper care .Households should followed proper child rearing style. They also focus on the overall concerns during their development to enhance the ART adherence. The primary care givers are expected to have an understanding about better parenting skills, proper guidance, and follow-up.

#### **5.1.2.4. The need of love and affection**

OVC on ART primarily needs love and affection from their parents/care givers. Especially the double orphan children have had high desire to have love and affection from their primary givers and equal treatment like their own children. Furthermore, the OVCs also need to have medical coverage and free health services from anywhere regarding their health need matters.

#### **5.1.2.5. The need of social support and affinity group**

As the research participant's explained that; the involvement and role of the community was not consistent and didn't similar for all individuals. Some of the peoples are emphatic and supportive while the others did not care about the OVCs and PLWHA. As a result, in order to be at equal foot the Government and other concerned actors should work for awareness rising to provide proper care and support for the children's.

A combined stresses associated with poverty such as inadequate housing, unemployment and forced relocation tend to aggravate the health condition of people who had already started their treatment. Effects of poverty such as shelter, hunger, violence from others, and lack of social support contribute immensely to non-adherence to ARV treatment (Kheswa, 2014).

#### **5.1.3. Possible suggestions for ART adherence**

Concerning to the possible suggestions, the research participants, discussant's and the KII would be suggested that: provision of adequate and HIV/AIDS focused trainings, establishing and strengthening peer to peer discussion, scale-up HIV Positive affinity group discussion, proper disclosure of HIV status, provision of detailed understanding on families about HIV/AIDS and ART adherence, provision of OI drug, hygiene and sanitation education,

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free access for school feeding, educational material support, provision of cash money, scale-up a block saving account for OVCs, provision of proper care and support, provision of love and affection, provision of parent education on better parenting skill and other income generating activities for the care givers and/or the OVCS are very vital to empower the OVCs and maintain the ART adherence at large.

The possible suggestions were given by the research participants discussant's and the KII was similar result with study conducted in Jimma Zone and selected woredas, on the situation of orphans and vulnerable children .Most of the families, relatives and the guardians of the OVC live in abject poverty. Hence, they need skill trainings on various economically gainful activities and star up capital (credit services free of interest rate). However, little attempt is made by very few organizations operating in the woredas/towns (Gudina et al., 2014).

## Chapter Six

### 6.1. Conclusion and social work Implication

#### 6.1.1. Conclusion

The challenges of OVC for ART adherence is not just like the same as expected from the outside. The children's was really surviving and growing with multi-faceted challenges. The challenges were faced did not only from their being orphan hood rather it had also from the complicated nature of the ART drug. The children's were in challenge of having proper love and affection, problem of basic needs, hygiene and sanitation, parental care and follow-up, absence of adult care giver, low understanding and awareness for ART adherence, absence of ART and clinical appointment reminder, stigma and discrimination, need of affinity group, lack of coordinated and integrated support, side effect of the drug with different opportunistic infection were their main once.

Besides, the care givers blaming nature for themselves as a cause (for some household's) and low level of free communication regarding the issue of ART adherence and disclosure were also created great challenges in children's life. As a result, the families needed to get income generating scheme trainings and better parenting skill, proper child rearing practice and to shape the children's growing properly. Moreover, besides the different skill training the children's was also acquired to get detained awareness about the ART adherence and its impact.

To maintain the ART adherence the families, the communities and the government had not yet work closely in a coordinated and integrated manner. In addition, the government was not properly strengthened and follow-up the existing systems to mainstream with the overall concerned bodies.

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Under such circumstances, it is important to describe and explain the challenges of OVCs for ART adherence to come up with evidence based interventions measures. As a result, in Ethiopia, nuclear and extended types of family structures were more important to provide basic support for the OVCs to maintain the ART adherence. Thus, to achieve the HIV/AIDS goals in time, the OVCs in on ART adherence needs greater attention and follow up, proper care and support, and love and affection in general from all the concerned bodies.

### **6.1.2. Social work Implication**

This study has implication from social work practice, education, research, and policy point of view.

#### **6.1.2. 1. Implication for Social Work Education**

Social workers work to advocate the wellbeing, participation, and healthy life of OVCs on ART. Though, creating awareness for the society about the challenges of Orphan and vulnerable children for ART adherence is vital at large. In addition, social workers should involve in rehabilitating the OVCs on ART adherence by broking the cultural, social, psychological and economic challenges to be a productive part of the society in the near future. To meet this, there should be adequate, well qualified, and competent social workers working in this issue and further in general. In this respect the role is to be left for higher institutions, especially for the school of social work. Therefore, the social workers can be intervening at individual, community, institution, government, and policy level gaps to fill with appropriate measure.

At the individual level, educating the infected individuals, families for detail understanding and knowledge, free communication and coping mechanisms for ART related

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challenges were very important to provide love and protection properly and equally. Besides, providing and facilitating income generating and capacity building training is too essential to empower them in all aspect.

At community level, creating comprehensive knowledge and understanding using the media and the different means is also crucial for maintain the ART adherence. Besides, the families, the neighbors, and the community members at lager should get detailed and comprehensive education, for the lives of OVCS, to improve their ART adherence in future. Encourage the community to provide the care and support system in comprehensive and integrated way that was started in different means and fragmented manner were too crucial.

At the government level, Social work training institutions need to train more professionals may not only at higher level but also providing short term training for volunteers who are committed to serve OVCS on ART adherence with minimal effort is excessively important.

### **6.1.2.2. Implications for Social Work Practice**

The finding of the study has also many implications for the need of social work practice. Social work practitioners could identify, assess, describe and evaluate the need for more health care and social work services in the community in the practical arena. In order to achieve this goal, this research implies the need to detailed and comprehensive understanding with factual information about the challenges of OVCS for ART adherence is very decisive. Health professional and educated volunteers working in the family and the community should provide special care and treatment, counselling and social support to maintain the ART adherence and to provide proper care and support for OVCS.

### **6.1.2. 3. Research implication**

As most literature revealed that, there is a research gap conducted at ART adherence. Hence the researchers indicate that research should be better to conducted contextually about the challenges of OVCs for ART adherence. The household's knowledge and understanding, practices of care and support, love and affection, child rearing and disclosure issues and others should be also described and researched before appropriate awareness programs are designed and implementation. This is best done through a study of qualitative research methods such as focus group discussion and quantitative methods such as surveys. Therefore, this study has a vital input for the issues studied further and fill the gaps were not addressed.

### **6.1.2.4. Implications for Policy**

From policy point of view, Social workers need to advocate for policy improvement and in creation of fertile ground to promote the care and supports services to relief the vast majority of OVC for ART adherence which is not yet looked by anyone more. Social workers should work on the communities, NGOs, the government in different sectors and grass root level should advocate for the regional and national government level to be benefited the OVCs for ART adherence from the policies designing.

The government should provide especial guarantee and attention for orphan and vulnerable children on ART and their affected families. The care and support service should also focus on the needs of OVCs and their age with easily accessed and available means. Moreover, the government should take the leading role to create comprehensive and detailed understanding about the ART adherence through using the media and develop a multi-sectorial partnership, response, and mainstreaming at all levels. Therefore, these legislative and policy gaps can be

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alleviated with the participation and advocacy of social workers in the national policy formulations.

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### *Appendices one*

Addis Ababa University

College of social science

Graduate school of social work

### ***Informed consent form***

Good morning/good afternoon. My name is ***Getenet Tadesse Haile*** and I am graduate student at Addis Ababa university graduate school of social work. Currently I am conducting thesis study titled “***challenges of Orphan and vulnerable children for Antiretroviral Treatment /ART /Adherence*** in Addis Ababa, at Gulele Sub city” for the partial fulfillment of master of social work (MSW).

The main objective of this study is; to describe and explore the challenges of Orphan and vulnerable children for ART adherence. As part of my study, I am coming to discuss the situation with you. I would use the information we generate to the best use of my research while simultaneously provide a clear picture of the challenges of Orphan and vulnerable children for ART /Antiretroviral Treatment /Adherence.

### ***Participation***

Participation in this study is entirely voluntary and you can choose not to participate in the interview or withdraw your consent any time at the middle of the interview.

***Confidentiality***

In the course of our discussion I want to assure you that, the information you will share, will be kept confidential and will be used only for educational purpose. The finding of this study will be presented and reported to the AAU for Graduate school of social work. When the findings are reported you will not be identified. You will be assigned with a pseudonym/code to protect your confidentiality. Demographic data and tape-recording will be kept in a locked cabinet during the study, but will be destroyed once the study is completed. In the tape-recording part I will not record your name so that your answers will be anonymous. If you are agreed to participate in this study, may I have your signature?

Participants signature \_\_\_\_\_ date \_\_\_\_/\_\_\_\_/\_\_\_\_

*Appendices Two****In-depth Interview guide I***

Good morning/good afternoon. My name is ***Getenet Tadesse Haile*** and I am graduate student at Addis Ababa university graduate school of social work. Currently I am conducting thesis study titled “***challenges of Orphan and vulnerable children for Antiretroviral Treatment / ART/ Adherence***” in Addis Ababa, at Gulele Sub city for the partial fulfillment of master of social work (MSW).

The following Questions are designed in order to conduct in-depth interview for HIV positive OVCs for this thesis study. The interview will be vital input for this study. Accordingly, I asked you to actively participate in this interview kindly. Moreover, your response is very much crucial for this study, I will appreciate very much your genuine answer for each question. If you have any question or comment you are free to share with the interviewer.

***Part I: Questions related to participants’ Personal Information***

Age\_\_\_\_\_

Sex\_\_\_\_\_ fill out by interviewer without asking participants

Marital status\_\_\_\_\_ (if anyone is married less than 18 years old)

Educational status\_\_\_\_\_

Religion you follow\_\_\_\_\_

Ethnicity/region\_\_\_\_\_

***Part II. Questions related to participants' ART status and challenge for Adherence***

1. Would you tell me about yourself from birth to now you know at all and/or based on what your parents/ others told you?
2. How do you know you have an HIV positive? When and where do you take HIV testing?
3. What symptom's or conditions did you understand and observe to take HIV testing and to start ART?
4. How did you get the diagnosis and treatment about ART?
5. How long you are taking ART and from where you are taking?
6. Did you interrupt your ART in the last time? If yes, when and how long you interrupt it?
7. Do you take your ART regularly, without interruption, from your start until now? If not, what are the challenges you forced to interrupt you?
8. Would you tell me your challenges regarding to your families, friends, neighbors and community?
9. Would you tell me your challenges regarding to economic and financial issues?
10. How do you describe your health challenges before and after taking ART drug?
11. What are the challenges you are facing in terms of age and gender issue? Probing question, do you think that special privilege/guarantee is needed for HIV positive OVCs?
12. Do you think that stigma and discriminations is a challenge for HIV positive OVCs? If yes, please share your lived experience you observed it and encountered?
13. Do you believe that holy water and ART drug opposed each other? Would you share your thinking and practice on it?( only Orthodox Christians and for whom who take part on it)

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*Questions related to the needs of OVC on ART adherence*

14. Would you tell me the needs of the OVCs on ART particularly and people live with HIV in general?
15. Would you tell me those persons who support and remind you to take your ART on time and helps you to meet your appointment in time?
16. Would you tell me about how your relationship seems like with your families, friends, neighbors and the larger communities at large?
17. Would you tell me how the health professional at the health center/ hospital you lead, support and encouraged to take the ART?
18. Would you tell me the person/s you fulfilled your basic needs like; food, shelter, educational materials, cloth, and others?
19. Do you think that the household income adequate to feed your family? (Probing question how many times/ a day the household members getting a meal?)

*Part IV: Questions related to participants' coping strategies*

20. How do you cope up the challenge related With ART adherence you come across?
21. Is there any assistance from government/organization and others in the time of your challenges?
22. What do you suggest to overcome the challenges related with OVCs ART adherence at the (individual, family community and government) level?
23. Do you want to add something important before we close our session?

*Thank you for your participation and cooperation!*

## CHALLENGES OF OVC FOR ART ADHERENCE

*Appendices Three****Focus group discussion guide II***

Good morning/good afternoon. My name is ***Getenet Tadesse Haile*** and I am graduate student at Addis Ababa university graduate school of social work. Currently, I am conducting thesis study titled “***challenges of Orphan and vulnerable children for Antiretroviral Treatment / ART/ Adherence***” in Addis Ababa, at Gulele Sub city for the partial fulfillment of master of social work (MSW).

The following questions are designed in order to conduct focus group discussion /FDG/.The separate OVC and their care givers FDG will be vital input for this study. Accordingly, I asked you to participate in this FGD. Moreover, your response is very much crucial for this study, I will appreciate very much your genuine answer for each question. Moreover, your presence and participation in this research is essential to learn and understand the situation deeply. If you have any question or comment you are free to share with the interviewer.

*Discussion point*

1. How do you understand ART adherence?
2. What are the major challenges you encountered OVC for ART adherence?
3. What are the major needs for OVCs for ART Adherence at individual, familial, community and government level?
4. What strategies would you suggest to improve OVCs ART adherence?
5. Anything left in the discussion and perceived important OVCs ART adherence issue?

***Thank you for your participation and cooperation!***

## CHALLENGES OF OVC FOR ART ADHERENCE

*Appendix Four****Key Informant Interview Guide III***

**Introduction** - statements stated on the above in-depth interview guide me and FGD guide II will be used as an introductory opening.

***Consent***

I'm going to ask you some questions related ***challenges of Orphan and vulnerable children for Antiretroviral Treatment / ART /***, which some people might find difficult to answer. Your responses are vital to make this study reliable and concrete. Your answers are completely confidential. Your honest answers to these questions will help me better understand the challenges of ART in general and the challenges of OVC for ART Adherence in particular.

Agree\_\_\_\_\_ signature \_\_\_\_\_ date\_\_\_\_\_

Personal information Sex\_\_\_\_\_ Educational status\_\_\_\_\_ Occupation\_\_\_\_\_

1. What are the major challenges that HIV positive people encounter in ART adherence and the OVCs in particular?
2. What are the major challenges you observed to happen in the service provision and client relationship?
3. What are the roles of the individual, the communities, NGOs and Government to achieve the three 90-90-90 HIV/AIDS goal in its specified time?
4. How do you describe the support and participation of the community to meet the needs of OVC for ART Adherence?
5. What are the major supports and services provided for OVCs to meet their basic needs and empower them at large in the future?

*Appendices Five****Observation Checklist***

1. Upon the consent of the participant the researcher will observe their physical conditions.
2. The researcher will observe participant while they are responding the open ended questions, and performing FGD.

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